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

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Faecal incontinence and the location of toilets are known to be a major concern of people with IBD1 yet most do not ask for help with symptoms. As part of a larger mixed methods postal and internet survey, we interviewed people who reported regularly experiencing faecal incontinence with their IBD.

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

PARTICIPANTS:
GENDER: Male 13, Female 15
DIAGNOSIS: Crohn’s (14); Crohn’s/Colitis (2); Ulcerative Colitis (12)
AGE: Mean 48.9 yrs; range 31-77 yrs

LOCATION:

STUDY DESIGN, MATERIALS and METHODS
28 semi-structured interviews in participants’ own homes (30-90 mins)
Schedule devised by authors from literature review and questionnaire responses from our larger survey
Digital audio recording and professional transcription
Consent obtained; ethics approval granted
Data analysed using thematic analysis

FINDINGS

THEME 1: SYMPTOMS
Sub-themes: unpredictability, urgency, bad odours, passive loss of stool, pain, sore skin, passing blood and mucus, triggers (food, stress, exercise, activity)
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 when people are there ’...’ but when it’s irregular it’s just very, very difficult to predict.’
Urgency: ‘I would think ‘Oh’ and I would know that I would have seconds — not minutes—seconds, to get to the loo.’
Odour: ‘... and sometimes the smell is horrendous’
Noise: ‘It’s not always just silent, it can be mucous and very noisy—it’s the embarrassment of it.’
Blood & Mucus: ‘You’ve also got the added worry of probably having nothing left inside your bowels, but you still have the blood and the mucous... It causes all sorts of problems— ulceration of the backside and the skin around it...

THEME 2: RESTRICTED LIVES
Sub-themes: housebound, toilet-mapping, cannot eat out, work or travel, limits on partner & family, toilet focus to everything
Financial limits: ‘I feel angry, annoyed, depressed even, because my wife is in a job which she doesn’t particularly like doing ... I feel as if I’ve trapped her into continuing to work because (my) ill-health early pension isn’t enough to actually live on!’...
Impact on family: ‘... quite often, (my wife) goes to places on her own or with the kids and I’m not involved ... whereas before, you see, we couldn’t see being apart.’
Toilets: ‘You can’t go out for a meal, you can’t go anywhere, but the caravan I’m fine, because I’ve got the toilet in the caravan’...

THEME 3: PRACTICAL ISSUES
Sub-themes: limited eating & food types, clean up kit / change of clothes, hiding / having to go home, access to toilets (public, disabled, work, queues, flushing), sleep disruption, little or no professional help / support, patchy IBD Nurse service
Limit eating: ‘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 straight away, I could.’
Public facilities: ‘You need not just toilet facilities... you need to be able to wash yourself’...
Consultant: ‘I got in contact with the GP and the GP gets in contact with the Consultant and it can take days to get something sorted...’...

THEME 4: EMOTIONAL & SOCIAL IMPACT
Sub-themes: partner attitude important; embarrassment, shame & humilation; fear over future coping; when, how and who to tell? Depression, anxiety, frustration, anger, acceptance, resignation; strengthens some people / couples; regrets—the life that could have been; parenting & relationships
Feelings: ‘It makes me terribly embarrassed if it happens when I’m with friends or loved ones ... frustrated as well, because you know you can’t do anything about it.’
Relationships: ‘I feel horrible ... disgusting ... dirty... he’s excellent with me but I feel embarrassed all the time. Sex life has gone out of the window’...
Social isolation: ‘I feel as if I have receded into the background.’
Social perceptions: ‘I think people associate incontinence with old people. You lose your bowel control as you get older... or you forget to go to the toilet when you’ve got dementia... people don’t think when you’re 20, 30, 40 that you could have a problem.’

DISCUSSION
Themes reflect many of those found in the non-IBD population with faecal incontinence
Pain, blood and mucus are particular to the IBD population
Urgency usually means ‘immediate’ with only a few seconds between the call to stool and defecation
Urgency and unpredictability take away peoples’ sense of control and lead to social, emotional, work-related and financial restrictions
Findings support earlier writing identifying the main concerns of people with IBD

REFERENCES

CONCLUDING MESSAGE
Faecal incontinence (FI) 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 FI impacts on peoples’ lives and the lives of those in their immediate social world, demonstrates how important it is that professionals begin to address this issue. 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 FI. It should also be possible to develop emotional and practical support strategies which enable people with IBD to cope better with their FI, and so reduce the overall negative effect that FI has on their wellbeing and quality of life.