

TITLE: Patient strategies for managing the vicious cycle of fatigue, pain, and urgency in inflammatory bowel disease: impact, planning and support

SHORT RUNNING TITLE: Fatigue, pain and urgency in IBD

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Authorship statement

CN, LD, BK: Conception and design of the study

LD, BK, MA, VVL, LS, JS, SW: acquisition of data

All authors: analysis and interpretation of data; drafting the article or revising it critically for important intellectual content; final approval of version to be submitted.

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ABSTRACT

Background Inflammatory Bowel Disease (IBD) causes inter-related symptoms of fatigue, pain and urgency which can persist in remission.

Aim To understand how people with IBD experience and self-manage these symptoms, to inform the future development of an online self-management programme.

Methods Using exploratory qualitative methods, we recruited participants from clinic and community settings. Focus groups, conducted across the UK, were audio recorded and professionally transcribed. Transcripts were analysed over four rounds using framework analysis. Eight patients were consulted to agree the final structure of data and themes.

Results Seven focus groups were held; five gave useable data. Twenty-six participants (15 female; ages 21 – 60 years; disease duration 2-40 years) with Crohn's Disease (n=10), ulcerative colitis (n=14) and IBD-Unclassified (n=2) attended one of these five focus groups. Three core themes emerged: *The Negative Impact of Symptoms, Positively Taking Control, and Seeking and Receiving Support.*

The persistent, often stark impact of multiple co-existing symptoms on physical and emotional wellbeing can force unwanted adjustments and limitations in working, social and intimate arenas of life. Unpredictable symptoms are challenging and impact each other in negative vicious cycles. Managing diet, pacing, accepting background levels of fatigue, pain and urgency, seeking support, exercising and attending to mental wellbeing, are all perceived as helpful in self-managing symptoms.

Conclusion Fatigue, pain, and urgency are troublesome for patients, especially in combination, suggesting that these should be addressed simultaneously by clinicians. Participants reported several strategies for self-management, providing patient-focused evidence to inform future development of a self-management intervention programme.

Keywords: fatigue; fecal incontinence; inflammatory bowel disease; pain; qualitative; self-management; urgency

INTRODUCTION

Inflammatory Bowel Disease (IBD), incorporating Crohn's disease (CD), ulcerative colitis (UC), and IBD-Unclassified (IBD-U), affects at least 300,000 in the UK¹ and millions more worldwide. These relapsing- remitting diseases usually start in childhood or young adulthood and cause unpredictable bouts of gut inflammation with acute illness, diarrhea and pain². Physiological and environmental factors are considered influential in the etiology and progression of IBD³⁻⁵. There remains no cure, and research focusses primarily on developing effective drugs and controlling inflammation in order to attain and maintain remission.

However, up to 41% of patients report continuing IBD-related fatigue⁶, 62% experience daily abdominal pain⁷ and up to 75% have difficulty with continence⁸ even when IBD is in remission. Thus, patients in remission frequently experience more than one of these symptoms simultaneously. Most evidence-based guidelines either do not mention these symptoms³ or do not recommend any interventions^{4,9}, possibly due to the lack of available evidence or effective options⁵. Whilst each symptom has been extensively investigated and reported individually, there is almost no evidence on how these symptoms co-exist or inter-relate.

Self-management, and interventions to improve fatigue, pain and urgency have been identified as priorities in recent consultations^{10,11}. As part of a large ongoing research program to develop and trial an online tailored intervention to support self-management of symptoms of fatigue, pain, and fecal urgency/incontinence in patients with IBD (the IBD-BOOST program; www.ibd-boost.org), we aimed to understand patients' perceptions and experiences of these three symptoms, and the self-management strategies they adopt. The research questions were:

1. What are the experiences of people with Inflammatory Bowel Disease of individual and multiple symptoms of fatigue, pain and incontinence?
2. How do people with IBD currently manage symptoms and what they have found helpful/unhelpful?

METHODS

We used exploratory qualitative research (EQR) to explore patient experiences of the three symptoms of interest; EQR is the methodology of choice when investigating an issue of interest for the first time, or where there is currently scarce evidence¹².

Recruitment

Participants were recruited from IBD clinics and patient databases at three UK hospitals (two in London, one in North West England), and from the community membership of the charity Crohn's and Colitis UK (CCUK). The clinical population was approached by their usual clinical staff (IBD Nurses, research nurses and doctors) at each patient's routine clinic or helpline telephone consultation. The charity population was informed of the study via the website, Facebook page and Twitter feeds of CCUK. Those interested in participating received information on how to contact the research team by telephone or email, to receive the full study details. If willing to participate, patients contacted the research team again by telephone or email. We aimed to recruit between 60 and 80 participants for eight focus groups (two groups per symptom, plus two for those experiencing combined symptoms).

Purposive maximum variation sampling was used to achieve demographic spread of participants with IBD (CD, UC, and IBD-U; both genders; range of ages; range of illness duration) and able to travel to one of our focus group sites.

Inclusion criteria

- aged at least 18 years; medically confirmed diagnosis of IBD (CD, UC, or IBD-U);
current or past experience of one or more symptoms of fatigue, pain and urgency /
fecal incontinence due to IBD

Exclusion criteria

- insufficient command of English to be able to understand study procedures, provide informed consent, or discuss their symptoms

Recruitment and data collection occurred simultaneously; further sampling ceased when nothing new emerged from the focus groups during data collection, and we were confident that saturation had been achieved¹².

Patient and public involvement (PPI) group

The PPI group members were a subset of a larger PPI team, recruited to support the IBD-BOOST program of research. The 'parent' PPI team were recruited from the membership of the charity CCUK, via their online research involvement page, and via email or text message to individuals from outpatient gastroenterology clinics who had taken part in previous studies at the host University and were willing to support future research activity. The PPI group for this study reviewed study documents, participated in development of the focus group topic guide, and individual and group data analysis to determine the final structure of themes and sub-themes, and reviewed the final manuscript for publication. They received training in qualitative analysis methods from the first author, who is an experienced qualitative researcher.

Data collection

Data were collected in 2018 via patient focus groups. These were delivered in four venues across the UK, facilitated and observed by a team of qualitative researchers (MA, BK, VVL, JS, LD, GM, SW, LS), and were audio recorded and professionally transcribed. Returned transcripts were checked for accuracy by MA and VVL, by reading through whilst listening to the original audio file. The word 'urgency' was used to refer to bowel control challenges including incontinence, as our previous experience confirmed this was a more acceptable phrase for participants than 'incontinence' (Dibley et al, *in press*). While urgency and incontinence are not the same, and either can be present without the other, our experience indicates that people with IBD often resist thinking of themselves as incontinent, but if invited to talk about urgency, will, if it is relevant to them, reveal the presence of incontinence. We therefore used the word 'urgency' as a euphemism for 'incontinence', to respect patient preference. The topic guide [Table 1] was developed in partnership with our PPI panel and informed by our previous studies^{6,13-16}, systematic reviews^{17,18} and knowledge of issues with development of online self-management programmes¹⁹⁻²¹. During focus groups, one team member facilitated the discussion whilst another acted as observer, taking field notes including a sketch of the layout, seating arrangement and first names of participants, and brief notes on the dialogue. These field notes were later used during analysis to identify speakers where this was unclear, or to add insight into dialogue which referred to something happening in the room.

Data analysis

All transcripts were anonymised and analysed using a framework analysis²² guided by the Common Sense Model of Illness Representations²³. The model proposes that illness perceptions directly influence coping strategies, which in turn influence outcomes.

In framework analysis, a list of codes is developed in advance of analysis, and then applied to all transcripts²⁴. It is the appropriate technique when there is a pre-determined purpose to the analysis - in this case, to identify impacts of symptoms of fatigue, pain and urgency and self-management strategies used by participants. Typically, the original framework [Table 2] is extended with new codes being added as analysis progresses; the final framework is then re-applied to each transcript and consequently there is rigorous application of the complete analysis framework to all transcripts. Analysis was conducted using Microsoft Word; each team member involved in analysis used a table template created by LD for each transcript they worked on. The table comprised four columns (coder's initials, focus group number, location of extracts, and data extract). Each coder worked their way systematically through the transcript, allocating meaningful extracts to codes pre-specified in the coding framework, and adding new codes if appropriate. An example of one section of a coding table is provided in Table 3. Following an agreed procedure for analysis to ensure appropriate focus and fidelity to the technique, seven members of the research team, including one PPI colleague, participated in data analysis; each transcript was analysed at least twice by different team members, and one (LD) analysed all transcripts.

LD then combined each of separate analyses into a coherent whole, producing one master data table (as per the template in Table 3); duplicate extracts (arising when different members of the analysis team coded the same extract identically) were removed from the final version, although duplicate coding demonstrates fidelity, robustness and trustworthiness in the coding process. The pattern of codes, leading to the emerging themes and descriptive labels were discussed and agreed at a team meeting; the allocation of data extracts to themes, and the overall arrangement of those themes, was then agreed in a collaborative workshop with eight members of the PPI group. As a result, the presentation of

themes was driven by patient opinion with only minor editing by the lead author (LD) to ensure clarity and avoid misinterpretation of theme meaning.

ETHICAL CONSIDERATIONS

Approval was granted by the UK National Research Ethics Service (Wales Research Ethics Committee 4; Ref: 17/WA/0349). Respondents to recruitment calls received the Participant Information Sheet. Participants agreed to a group consent statement read out at the start of each focus group, and also provided written informed consent immediately before data collection. Participants were reimbursed for expenses incurred by attending the focus groups.

RESULTS

Of the 195 people who were invited to participate, 54 (27%) responded. Of these, 16 withdrew either due to illness or without giving a reason, leaving 38 people who agreed to participate.

Of the seven focus groups (FG), one recording (five participants) was lost due to equipment failure; in another, the facilitator struggled to keep the seven participants focussed on the topic and whilst rich data on life with IBD were captured, the core symptoms of interest were not directly addressed; the team therefore agreed not to analyse the data from these 12 participants. Results are therefore presented from data gathered from 26 participants (15 female; ages 21 – 60 years [mean age 34.8 years]; disease duration 2-40 years [mean duration 12.5 years]) with Crohn's Disease (n=10), ulcerative colitis (n=14) and IBD-Unclassified (n=2) who each attended one of five focus groups (N=4, 7, 6, 6 & 3), identified as

FG 1,2,3,4 and 5. Sixty-three percent of participants were White/White British, 7.5% were Asian/Asian British, 7.5% were Black/Black British, 7.5% were of mixed ethnicity, and 14.5% did not specify their ethnic group. All participants except one (who did not know) verified that their diagnosis had been confirmed by endoscopy [Table 4]. We did not collect disease activity data, because we were not seeking to link symptom activity to a specific point in time, but to gain an understanding of the longer term, everyday experiences of living with the three symptoms of pain, fatigue and urgency. The demographic data [Table 4] also indicated that participants rarely experienced either fatigue, or pain, or urgency (incontinence) as an isolated symptom, so we used all focus groups to explore all symptoms, instead of addressing each symptom separately as originally planned.

Three core themes, each with several sub-themes, emerged [Figure 1]:

- *The Impact of Symptoms*: perceived causes and knock-on effects across symptoms, persistence and unpredictability of symptoms, effect on identity, and unwanted psychosocial, emotional and intimate consequences
- *Positively Taking Control*: the different ways in which participants achieve control, their coping strategies and self-appraisal of their situation, the adaptations and changes they choose to make to manage these symptoms
- *Seeking and Receiving Support*: the value of receiving understanding from friends and family, work managers and colleagues, and health care practitioners, the practices these people offer which are helpful, and the impact on the person with IBD when symptom-related needs are not recognised

In keeping with qualitative reporting standards¹⁶ findings are presented using verbatim data extracts; participants are represented in square brackets by gender (F= female, M=male) and

source (Focus group (FG) 1,2, 3,4, or 5), for example: [F; FG3]. A single exemplar quote may be used to illustrate a point raised by several participants.

Theme 1: The Impact of Symptoms

Participants were unable to discuss fatigue, pain, and urgency separately from their overall experience of IBD, and were also often unable to describe symptoms distinctly, reporting a complex inter-relationship which created a vicious cycle between all three:

'I think each symptom and reaction begets another one. It's a chain reaction for me and it can start with any single one ... I think any number of things can cause the chain reaction but it's definitely a chain, I never get one symptom alone by itself' [M; FG4]

The disease, and these symptoms, had a significant negative impact on their lives. The relentless presence of symptoms, factors which aggravated their symptoms, the consequences, unpredictability and uncertainty of symptoms and how these impact on their identity are described under sub-headings below.

Relentless presence of symptoms

Inflammatory Bowel Disease exerts a significant disease burden on patients, including but not limited to anxiety about the condition and likelihood of flares, regularly taking powerful medications, clinic appointments and for some, stoma care. The enduring and relentless impact of the three symptoms add to this burden: *'I have [pain, fatigue, urgency] all the time, no matter how well I am or how deep in a flare I am or not'* [F; FG4]. Either singly or in combination, many reported that the fatigue, pain and urgency are constantly with them: *'Every day I'm tired ... for 18 years now I guess pretty much every day it's just this bone weariness'* [M; FG2]. The durability of these symptoms indicates that for some, disease

status is irrelevant: *'My pain scale I'd say is always about three [out of 10] no matter if I have ulceration or not'* [F; FG4].

Aggravators of symptoms

Participants identified a range of factors which they believed contributed to their symptoms.

Being 'run down', stressed and anxious had consequences, especially on urgency: *'I know what sets me off, I know that if I feel stressed out I will make myself feel ill, my stomach will be in knots, it will feel like someone is literally grabbing my intestines and giving them a good pull. And I know I will need to go to the toilet immediately'* [M: FG2]

Increased urgency resulting in many more trips to the toilet would then affect energy levels:

'Every time I am very, very stressed it obviously messes my bowels, so I'll have to poop 500 times a day and obviously that will make me tired. It's a never-ending cycle.' [F; FG4]

This 'knock-on' effect and vicious cycle of symptoms – such as the urgency contributing to fatigue, fatigue worsening pain, pain then triggering urgency – was central to participants' experiences and suggests that these symptoms are rarely experienced separately, but as a complex inter-related 'mesh'.

Diet and eating aggravated symptoms, particularly urgency, but also pain levels: *'The pain, I don't know what to do with that, but I've altered my diet a little bit, so I don't eat broccoli, I don't eat cabbage, I don't eat anything that causes those pains that we're all familiar with'* [F; FG3]

A few participants felt that medications prescribed for their IBD could make these specific symptoms worse: *'I think high doses of steroids and all the medication contributes to you feeling unwell anyway and the tiredness'* [F; FG3]

Whilst stress and anxiety were common shared aggravators, individuals responded to different foods and medications in different ways so that these variously caused problems for some, and not others.

Consequences of symptoms

The consequence of these often-co-occurring symptoms were wide-ranging and frequently unpredictable, affecting participants' ability to work and socialise, to function in a way they would describe as normal, or even simply feel confident enough in their bowel control to be able to leave the house: *'For me it's definitely urgency - and then pain and fatigue. Urgency does stop you from doing anything, it's a real fear'* [F; FG5]. Participants reported having to manage their social life to accommodate the impact of fatigue and urgency: *'I do go out but just on Friday and Saturday when I know that I can rest or spend as long as I need to in the toilet the next day without any worries ... because mornings are always the worst.'* [M; FG1]

Whilst some avoided social activities on weekday evenings, others found that their social circle had narrowed, or disappeared altogether: *'[Fatigue] has inevitably meant that I've drifted apart from a lot of people as well, people that I saw regularly or often I just don't see them anymore because I haven't got the energy to go and see them.'* [M; FG1]

Participants were also frustrated when their efforts to adopt a healthy lifestyle made their symptoms worse: *'I tried to go to the gym and I was having to rush to the loo all the time, so I just thought this isn't worth it, there's no way I can do this.'* [M; FG3]

Constantly having to deal with symptom-related concerns could have a detrimental effect on mental health: *'If I don't know where a toilet is I can't socialise with people because if [incontinence] happens I'll freeze, I won't know where I'm going ... it's like your brain gets*

rewired to pre-plan everything and that kind of re-wiring that went on caused me to have a lot of anxiety, especially socially' [F; FG4]

Some participants had changed their work type or pattern because of relentless symptoms:

'I used to work in a number of different schools and obviously school starts early and sometimes I'd have parents meetings and I couldn't maintain that work because I was driving to different schools, and being in the car if you need to nip to the loo ... so, yes, I had to change.' [F; FG1]

Others reported concerns about fatigue leading to under-performing at work: *'There are days when you are just shut off [at work] but it's like you can't process the information that's going on and you sit in front of the screen and you just can't process. I feel really bad about that'* [F; FG4]. For others, the three symptoms were reported to negatively impact on intimacy: *'I'm quite young and have been with my husband for six or seven years ... all you feel is ill, so you look at yourself and you don't feel attractive anyway, you don't have the libido because you don't have the energy ... it's almost like you've got to exercise [practice] feeling intimate with someone ... but you get out of it and you just don't [do it] anymore ...'* [F; FG3]. Treatments, the general impact of IBD, and these symptoms are disruptive: *'It's not just the setons - I feel urghh ... I just feel horrible, I feel tired, I feel in pain, I don't feel sexy'* [F; FG5].

Unpredictability and uncertainty due to symptoms

For many, the inability to confidently plan activities outside of the home because of these symptoms was a cause of both distress and frustration: *'If I want to go down to the pub, if I want to go outside [the house] urgency can become a problem'* [M; FG5]. Others also reported the lack of reliable pattern between their activities and symptoms as problematic:

'One thing I really struggle with is fatigue and not being able to do anything about it, or not understanding one day you might wake up and feel really fatigued and the next day you felt that you've done the same thing, but you're not [fatigued]. It's just very much 'Well what have I done differently?' and trying to think it through - maybe there's nothing that you've done differently it's just that today's a different day. I think I struggle with that quite a bit. [F;FG5]

For a few participants, medications to treat IBD which would be expected to also resolve these symptoms were not always, or stopped being, effective: *'I haven't yet managed to find a medication I can tolerate even though I've had colitis for 11 years now' [M; FG1]*

This unpredictability around the effectiveness of medications caused uncertainty and fear for the future, with participants concerned about how they would manage their symptoms when *'all else has failed'*.

Identity and symptoms

Whilst a diagnosis of IBD was understood to have influenced identity development amongst those diagnosed in childhood, the three symptoms were also perceived to affect adult identity by negatively affecting the perceptions others had of participants. For some, identity was clearly linked to each of the symptoms, and included believing themselves to have an undesirable characteristic: *'I'm always tired but I've spent all my life thinking I'm lazy' [M; FG3]*, understanding their life with constant pain as being normal: *'I've got to a point where [pain is] the norm [M; FG3]*; and feeling themselves to be seen as unreliable due to regular dashes to the toilet: *'I didn't tell people at work, I didn't tell my friends and that's really difficult, because when you are trying to hide it, it's even worse in a way because they don't*

know why you are rushing off all the time.' [F; FG1]. Others' perceptions and expectations of the kind of person one is, and how one should behave, caused concern to participants:

'[Incontinence] was one of the things I found hardest because everyone just looks and me and goes, 'You are so young' ... they don't expect me to have all these issues' [F; FG2]. These concerns were particularly relevant when dealing with others' reactions: *'Because we go through it every day ...you get numb to it [but] other people do find it hard to hear. It's not worth being honest sometimes because then it makes you feel worse about yourself because of the way they've reacted'* [F; FG4]. Others reported the challenges of having repeated, unchanging conversations with work colleagues: *'The problem is if you are ill all the time, it's so boring for you and it's like a running commentary. I've worked with some of [my work colleagues] for ten years, [when they say] "how are you feeling today?" What do I say? No better, again. Another day, no better. A little bit worse today. Actually, in constant pain, what do you want to do about it?'* [F; FG4].

Social expectations define the type of person one is meant to be. Generally, this means abiding by the rules, including those of hygiene and containment. People can feel stigmatised if their symptoms are interpreted by others as 'breaking the social rules.' These rules are so deeply embedded in many cultures, that people who cannot observe the rules can be urged to hide that fact: *'I don't think my parents meant to make me ashamed of it, but they were like, 'just keep it to yourself, it's just a private thing' and I was like, 'OK''* [M; FG4].

Theme 2: Positively taking control of symptoms

Participants' experiences around taking control of their symptoms were represented by two distinct factors: the cognitive influence of self-appraisal which impacts their attitude towards

their situation, and the practical aspects of control, in which they spoke about the strategies they employ to manage their symptoms.

Self-appraisal

Participants reported several positive moments and perspectives which had become 'turning points' in their life with IBD, putting them on the path to doing what they could to get their symptoms under control. This included a 'call to action', when they reached a point where they recognised a change was needed: *'It just got to the point where I realised unless I change my job and do something else that doesn't cause me as much stress, I'm always going to have this issue [with urgency]'* [M; FG1]. Similar decisions were reached for addressing pain: *'I keep thinking to myself, I can't go on walking through life in this fuzzy state of being half asleep all the time, bogged down with painkillers'* [F; FG2] and also fatigue: *'I went to a nutritionist [who] said 'You can continue as you are and that's the pattern, or you can change your life'. So that's kind of the moment when I changed my life, as I realised I needed to, I couldn't keep going at the same pace, I just didn't have the energy or the stamina'* [M; FG2]

Others who had not yet found the way forward, still recognised that a change was needed, and were searching for it: *'How can I actually help myself? ... because through all this, the pain, the fatigue, the incontinence, how can I actually help myself is a question that I constantly find myself asking'* [F; FG2]

Acceptance was reported as a key component of living well with these three symptoms: *'Being tired and then trying to do a full time job - I used to just do extra hours and I'd get home knackered and I think one of the things I've learnt through having IBD is you need to switch off'* [F; FG4]. Others felt that: *'Pain is annoying, but it's manageable most of the time'* [F; FG4], whilst a single, potentially socially devastating event was enough to effect a change

to manage urgency: *'Over the years I noticed [an increasing inability] to have dairy, and I found that out one lovely day in the middle of a lecture with a hot coffee, it [fecal incontinence] was not fun. But after that I truly learnt my lesson, no more milk, especially not hot milk, even when I'm really tempted. I feel like sometimes it takes one really bad experience for you to fully accept that this is off limits'* [F; FG2]

Once a situation or a need for change was accepted, the adaptation to incorporate that change could take place: *'So I went freelance, went self-employed basically and moved out of town – I live by the coast now. And I'm self-employed because I found also being in an office environment was very difficult when you have to go to the toilet a lot'* [M; FG1]

Similarly, participants had made, or were working on making adaptations to cope with fatigue: *'I'm probably just starting to deal with my various issues and that's part of it, coming home from work after a real full on day and being able to do what's right for me now'* [F; FG3]

Aspects of control

Participants reported several practical strategies they adopt to self-manage their symptoms of fatigue, pain and urgency, generating a sense of control over their situation. Many had identified ways of dealing with the stress and anxiety which had been reported as a key influence on urgency: *'I definitely started trying to take more care of myself mentally, so I do yoga once a week, I do a lot of meditation stuff. Now that things are a little bit more under control I don't feel so stressed about it'* [F; FG1]. Yoga, Pilates, meditation, mindfulness and counselling were all reported as beneficial in reducing stress and anxiety, and improving mental wellbeing: *'There is someone I go and talk to who said, 'It's OK to be frustrated - it's absolutely OK; it's not OK to keep it all in' ... you don't realise that - there are times when I feel like I'm being too negative, because all I can think about is, 'I'm in pain, I'm tired, boo hoo,*

woe is me!' And I go and speak to the counsellor ... [and] he reminds that it's OK to have these feelings and not to bottle them up, and not to ... almost beat myself up for feeling bad that I'm tired yet again, it's day 15 of [my] tired episode and still no change' [F; FG2]

Others reported that they have taken positive steps to maintain control over symptoms, and thus retain their sense of emotional control. Positive steps included monitoring their activity levels to ensure troublesome symptoms didn't resurface: *'So even if I've got to work at home I make sure that I don't put myself in a position where I need to be working at full [ordinary] pace, because of that bone weariness tiredness. It's always underneath, and if you're not careful it will come up' [M; FG1].*

Heat, applied via hot baths, hot pads or water bottles, was used to manage pain: *'I sleep with a hot water bottle [against my abdomen] almost all year round, because ... the heat really helps I find. That's the first thing, heat to kind of relax and then the codeine' [F; FG2].*

Symptom control also came from medications, and by pacing oneself to manage energy: *'The spoon theory proposes that you have a certain number of spoons per day [to represent your energy]. Once you run through your spoons, that is your spoons for the day and any more would mean you have less spoons for the next day, so it's kind of like rationing. Your energy is a certain amount and say one day you may skip walking the dog, the dog will be upset about it, but because you skipped walking the dog you'll have more energy to do something else. If you did something else and walk the dog you'd be wrecked for tomorrow, and it's just not worth it ... leave the dog' [F; FG2]*

Diet was influential, and those who had gained successful control had worked out the specific food items which either exacerbated or improved their symptoms. Others recommended monitoring intake and symptoms, to try and identify patterns between these: *'Keep a diary.*

Keep a diary of your symptoms, what triggers them ... we're all individuals and unique in how we respond to different types of food, I don't think there's any one set piece of advice that can be dished out to all patients. So yes, it is through trial and error that you learn' [M; FG2].

Exercise was also reported as beneficial mentally, giving people the feeling that they can still achieve something despite their IBD: *'I'll get home [after exercising] and I'll think I feel good because I did exercise like a normal person would, and I'm not going to close down at 9pm because I've still got some endorphins' [M; FG4]*

Different types of exercise suited different people, with running, walking, and going to the gym being discussed. As well as the perceived physical benefits, many commented on the benefits to mental wellbeing: *'Exercise is as much of a mental release and relief as it is a physical one' [M; FG2].* Exercise was reported as particularly beneficial for those dealing with pain and fatigue: *'I really find a walk [helps] if I'm feeling a lot of pain, but exercise just really helps me in general. I've always been fairly active, and I found that if I'm really not feeling great and I make myself go [for a walk] it just feels better' [F; FG5].*

Theme 3: Seeking and Receiving Support

In this final theme, participants described the many ways in which they seek support to manage their symptoms of fatigue, pain and urgency, although not always with success. The challenges of not having symptom-related needs recognised, and the benefits of gaining understanding and support, have a notable bearing on living with these three symptoms.

Needs not recognised

Participants had sought help in managing their symptoms from numerous sources, including

family, friends and the general public, but even the pressing concern of imminent incontinence could not always garner assistance: *'There's a queue for the Ladies toilets and I'll say I have to go and I'll be very frank and honest and say 'I'm going to shit myself, I need to go to the toilet' or something like that and they'll say 'we can't do anything'. Then I'll say, 'oh I'm pregnant' and they'll go, 'oh of course'. Don't get me wrong I'm happy they treat pregnant women well but it's shocking that I have to lie about being pregnant'* [F; FG4]

Similarly, participants found that others really did not understand the debilitating impact of fatigue: *'This is not just me feeling a little bit, oh I've just had a bit of a late night, it's quite hard to explain it to people so they understand it. I'm not just a little bit tired ... I'm really struggling here'* [F; FG5]. Others reported unsupportive and unhelpful attitudes from employers and work colleagues: *'My work is unfortunately quite inflexible, I don't get a massive amount of leave, I don't even work flexi-time, so I can't have a lie in if I need to [because of fatigue]'* [F; FG3]. Participants struggled to talk about needing support with symptoms without revealing their IBD. For many, employers were inflexible, perceived as unlikely to be sympathetic or to maintain confidentiality. There was concern that revealing oneself to be chronically ill would have a detrimental effect on their career, and cause others to have a negative perception of them as a work colleague.

Participants also reported not receiving the help they needed with symptom management from clinicians. For some, requests for help were actively denied: *'[Doctors] don't really offer to refer you to dieticians or anyone else because I've asked but they [say], 'Oh no, the medication should do it''* [M; FG1]. Others felt that their requests for support were always, and only, addressed from the biological perspective, leading to frustration and distress: *'Even if I say to my nurses or my doctor, I'm more tired than normal, they'll look at my blood test*

results and say 'Everything's fine, your vitamin D levels are fine,' or they'll say, 'We'll give you some supplements, take some supplements, this will make you feel better, ...' I'm so frustrated at the people who are supposed to help me because if I'm telling you I'm really tired and I spend 20 hours a day sleeping, why aren't you doing anything about it? Or if you [health care practitioners] can't do anything, just own up to it, say "There is nothing I can do about it"' [F; FG2]. Failing to recognise when patients are seeking an holistic approach to their symptoms, could have serious consequences, including deterring patients from engaging with necessary clinical services, to the potential detriment of their overall health: 'When I said I want to try and manage [my symptoms] through diet I was almost laughed at, at the time. And it really put me off actually going to the hospital and seeing the consultant, because I just felt they weren't interested in my approach or they weren't interested in listening to how I wanted to deal with it, so actually I didn't go to hospital for the longest time' [F; FG1]

Gaining understanding and support

The negative experiences reported above were counterbalanced in some cases by supportive responses from friends, family and the public, from work managers, colleagues and school personnel and peers, and from clinicians and social networks.

Participants spoke frequently about the benefits of telling others about their IBD, which resulted in those others understanding when the illness, and these specific symptoms, caused problems: '[Telling others] is liberating in the fact that I do tend to flake a lot inevitably [due to fatigue] and there have been some parties or dinners or events and I've said look I can't come. But because I've told them, they are aware of what I have and they are much more understanding' [M; FG1]. Knowing that support was there, even if they didn't draw on it, was reassuring for participants: 'I've now told my boyfriend and best friends and

it's good because sometimes you are on a train and you just feel really uncomfortable and I'll just stop talking because I'm trying to control [the urgency] and they'll ask if I'm ok. It's quite good that they know that you are uncomfortable' [F; FG5]

Similarly, there were examples of positive responses from employers being flexible to enable participants to work around the challenges of their illness and symptoms: *'My workplace luckily brought in flexible working and home working and my boss was quite supportive with me working from home when I needed to. So, the days where I was going to the toilet 14 times a day, the bathroom was two steps away from where I was sat and I could sit in my pyjamas if I needed to with my hot water bottle; having the option to do that is so important' [F; FG4]*

All participants who reported supportive responses when revealing information about their illness and these three symptoms which accompany it, had mostly received those responses from people with whom they had their important personal, social and work relationships.

Although some participants had not felt supported by clinicians, others reported beneficial interactions which made them feel listened to: *'The [clinicians] will ask 'how has it been?' and I tell them, I'll make a list, this is what's happened, I've been [to the toilet] this many times, I've had this problem' [M; FG1].* In particular, IBD specialist nurses were acknowledged as a valuable source of support: *'[IBD nurses] are not dismissive and they'll answer your questions and make you feel at ease rather than, 'yes, yes, see you in six months' "[F; FG5].*

Social networks were considered beneficial; participants learnt about managing IBD and the associated symptoms of fatigue, pain and urgency from others either in face to face meetings run by local support groups, or via internet chat rooms and support pages: *'When you talk to*

somebody who understands it definitely helps a lot. Other people have recommended probiotics to me, or talked about other medications or even [exercising] because different things obviously work for different people and to get this under control you have to try as much as you can, so I think it really helps when you have someone else who has been there, who understands. It makes a big difference' [M; FG1]. Participants agreed unanimously that: *'Nothing helps more than talking to someone else that has [IBD] ... I come out of those [meetings] feeling really good because you can just talk about it really openly and also you get to hear about what other people are doing and experiencing'* [F; FG1].

DISCUSSION

Although the co-occurrence of symptoms has been reported previously²⁵⁻²⁷, and recent research on IBD pain has demonstrated a cycle of symptoms¹³, as far as we know, this is the first study to report the inter-relationship between these three common symptoms of fatigue, pain and urgency in IBD, and that improvement or deterioration in any one of the three symptoms, affects the other two. Similar patterns are also seen in patients with Irritable Bowel Syndrome (IBS) where attention to diet, for example, can also relieve abdominal pain and improve bowel symptoms of constipation or diarrhoea²⁸.

The findings demonstrate that there is a compound effect of having two or three of the symptoms of fatigue, pain and urgency, which is greater than each symptom in isolation. Few participants discussed one symptom alone, with most describing a complex web of interrelated symptoms which create a vicious cycle: pain compounds fatigue, fatigue compounds urgency, and urgency adds to fatigue and pain. This inter-relationship suggests that targeting one symptom alone is unlikely to be successful, and that co-existing symptoms should be addressed simultaneously. It also suggests that even if patients only mention one

of these symptoms, there is every chance that they are also troubled to some extent by the remaining two symptoms. Fatigue and pain were easier to discuss than urgency / incontinence yet were demonstrated to have a significant impact on bowel control. Patients who report fatigue and/or pain may also benefit from being asked about urgency / incontinence. Clinicians may usefully assess these symptoms in their patients using brief tools that are available for assessing fatigue, pain and urgency / incontinence, and may be useful in clinical practice. As a minimum, clinicians could simply ask patients if these symptoms are problematic, and if these inter-relate. Simultaneous assessment can achieve a better understanding of the impact that each symptom has on physical and psychological functioning, and of how the patient responds to these symptoms. Symptom assessment, treatment and long-term management may benefit from psychological input in conjunction with medical management.

The Common Sense Model of Illness Representations²³ provides a useful framework for understanding participants' experiences of life with these three symptoms. Whilst it is not unexpected that findings mapped onto the Model, given its role as the framework for the analysis, these are nonetheless revealing. Illness perceptions amongst these participants (for example, fighting against or accepting the diagnosis and the symptoms; avoiding or accessing healthcare; being ruled by or taking control of their IBD) directly influenced their coping strategies, which in turn influenced outcomes. For example, participants who accepted their IBD and symptoms, and who had strategies for coping such as talking with partners and those in close relationships with them about their symptoms, were able to then create a support network which helped them manage the challenges that fatigue, pain and urgency presented. Even so, the persistent unpredictability of symptoms added a permanent

undercurrent of uncertainty to participants' lives. Although participants did not use the term 'self-management,' their description of activities and attitudes they adopted to manage fatigue, pain and urgency were indicative of an extensive array of self-management behaviours^{29,30}.

The importance of social support and resilience in IBD is also well-documented³¹⁻³³, and the findings of this study further indicate the need to provide accessible resources to help patients develop effective ways of self-managing these three troublesome symptoms. This may include access to specialist dieticians, counselling and other psychological therapies, and wellbeing and relaxation activities which reduce stress.

Strengths and Limitations

Despite robust efforts to recruit, and willingness to participate, several respondents who agreed to take part in a focus group were unable to do so, usually due to illness. We were unable to reschedule focus groups to accommodate those who missed the events but did offer the opportunity to participate in a one to one interview for the next phase of the programme of research (reported elsewhere). Despite the lower than expected numbers, the plentiful and complex data obtained from the remaining participants across the five focus groups suggested that data were sufficiently saturated, ie: that sufficient thick, rich data³⁴ was produced to enable us to answer the research questions, with no new topics emerging during later focus groups, and no discernible gaps in the coding; we therefore did not need to sample further. We did not conduct separate focus groups for participants with CD and UC, and found no obvious differences in their experiences of, and methods of managing, the symptoms of interest. The robust analysis of data by the study team and members of the PPI

group enhanced credibility and trustworthiness, with the final themes and sub-themes being a consensus of all who contributed to analysis.

CONCLUSION

The symptoms of fatigue, pain and urgency are liberally reported, individually, within the academic and medical literature. As far as we know, this is the first study to report the complex interrelationship and compound effect of all three, suggesting that these need to be managed simultaneously, by the clinician and by the patient.

The persistent impact of these uncertain and unpredictable symptoms on physical and emotional wellbeing can be stark, forcing unwanted adjustments and limitations in working, social and intimate areas of life. Symptoms rarely occur in isolation, and often have a cumulative effect on each other. Managing diet, pacing oneself, accepting background levels of these three symptoms, seeking support, exercising, and attending to mental wellbeing are perceived as helpful in managing symptoms. Several strategies for self-management were identified, providing patient-focused evidence to inform the future development of an online intervention programme for self-management of these symptoms.

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