Healthcare professionals’ perceptions of fatigue experienced by people with IBD

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Phenomenological study

Abstract

Background and aims: Fatigue is one of the top complaints of people with inflammatory bowel disease (IBD); however this is often not addressed in clinical consultations. This study aimed to gain an understanding of healthcare practitioners’ (HCPs) perception of IBD fatigue as experienced by people with IBD.

Methods: Descriptive phenomenology was conducted with 20 HCPs who work with people with IBD. In-depth semi-structured interviews were audio recorded and transcribed verbatim. Colazzi’s framework was used to analyse data.

Results: Three themes and several sub-themes were identified. The main themes were: the phenomenon of fatigue as perceived by HCPs; the impact of fatigue on patients’ lives; and the methods used by HCPs to deal with fatigue. Fatigue was identified as an important, but difficult and frustrating, symptom to understand. HCPs reported that fatigue impacts on the emotional, private and public aspects of patients’ functioning, however there were few methods suggested on how to assess and manage the fatigue. Many expressed frustration at not being able to help more.

Conclusions: The study identified a gap in HCPs’ knowledge and their understanding of the complexity of IBD fatigue and the full impact that IBD fatigue has on people’s lives. There is a need for more research-generated evidence to enhance our understanding of the concept and the factors associated with IBD fatigue. Advances in the assessment and management of this complicated and poorly understood clinical symptom are needed in order to help enable HCPs to provide better quality care to people affected by IBD and IBD fatigue.

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1. Introduction

Treatment strategies in inflammatory bowel disease (IBD) have predominantly focused on improving and resolving inflammation and its symptomatic consequences such as diarrhoea, abdominal pain, rectal bleeding and anaemia. Chronic symptoms such as fatigue have received relatively little attention from healthcare professionals (HCPs). However, a lack of energy has emerged as something of concern to IBD patients and low energy levels are the third highest rated (out of 25 items) IBD-related concern after uncertainty about the disease and the effects of medication. Fatigue is reported to be the most troublesome symptom when IBD is in remission, affecting on average 40% of participants without being influenced by researchers’ who assess them. Therefore descriptive phenomenology was chosen as the most appropriate as it gives voice to the participants without being influenced by researchers’ preconceptions. The study, advertised via the Crohn’s & Colitis UK charity Newsletter and an IBD Specialist Nurses’ Newsletter asked for volunteers. No doctors or pharmacists responded. A snowballing method was used to identify and approach further participants from other professional groups. Purposive sampling was used to identify a range of professionals (gastroenterologists, IBD nurses, general practitioners (GPs), dietitians, psychologists and pharmacists). Inclusion criteria were: frequent contact with people with IBD and regularly provided follow-up care, with a minimum 6 month experience of working in gastroenterology (in the case of GPs, having special interest in gastroenterology). Data were collected through in-depth semi-structured interviews conducted with HCPs, between June and December 2012. All participants were given a choice of telephone or face-to-face interview and the majority (16 out of 20) chose to be interviewed over the telephone, four were interviewed face-to-face. For the interview guide see Table 1.

Open ended questioning was used with reflective questioning to seek further information and clarification of the data.

3. Ethical considerations

The local university ethics committee approved the study (Ref number: PNM/09/110-93). All participants who expressed an interest in being interviewed received written information electronically and a consent form prior to the interview: all returned a signed consent form and agreed to audio recording. Names of individuals are omitted to protect their confidentiality.

<table>
<thead>
<tr>
<th>Stage of interview</th>
<th>Example of probes</th>
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<tbody>
<tr>
<td>Opening statement</td>
<td>Please can you tell me what your professional background is and how long have you been working with IBD patients?</td>
</tr>
<tr>
<td>Follow-up statement</td>
<td>What are the main symptoms/problems that patients with IBD complain about?</td>
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<tr>
<td>Reflective questioning</td>
<td>Do many patients complain about fatigue? What language/terminology do they use to talk about their experience of fatigue? What advice do you give to patients if they report fatigue?</td>
</tr>
<tr>
<td>Closure</td>
<td>You have used the word ‘lethargy’. Can you tell me what does this term mean to you? Does lethargy differ from fatigue? You have mentioned ‘other factors’ that may affect fatigue. Can you tell me more about the other factors? Is there anything else that you would like to add or talk about?</td>
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Table 1 Semi-structured interview guide.
4. Rigour

Rigour in qualitative research is concerned with the systematic process of collecting and analysing the data. WCD collected all data and ensured consistency in approach across all interviews. Interviews were audio recorded and transcribed verbatim by a professional transcriber. Colazzi's 7 step framework was utilised to analyse the data.14 The steps of Colazzi's framework and how they were implemented in the process of the data analysis are presented in Box 1.

Each author analysed at least 50% of the transcripts. The authors met face to face twice and had multiple telephone and electronic conversations to refine and agree themes. Involvement of several independent researchers (healthcare professionals with and without IBD experience and employees of an IBD charity) in the analysis and interpretation of the data aimed to reduce personal bias and produce trustworthy results. Verbatim quotes, selected as reflecting respondents' views are given (in italics) to illustrate themes. Quotes are referenced by respondent's professional background and allocated code number to demonstrate that data from all participants are used.

5. Results

Twenty HCPs were recruited and interviewed: 8 IBD nurses, 2 gastroenterologists, 3 dietitians, 2 general practitioners, 2 hospital pharmacists, and 3 psychological care practitioners (one psychologist, one counsellor and one psychiatrist). Ten practitioners were based at teaching hospitals, 8 at general hospitals, and 2 in primary care. The median time since qualifying was 19.1 years (range 4–38) and median experience in gastroenterology was 8.7 (range 2–25) years.

The data analysis resulted in identifying three main themes and eleven sub-themes (Table 2).

5.1. Theme 1: phenomenon of fatigue as perceived by HCPs

5.1.1. Sub-theme 1: description of fatigue

The study participants reported problems describing and understanding fatigue. They perceived fatigue as 'such a complicated and complex thing' (GP, HCP15). Respondents suggested that the hidden, subjective and non-specific nature of fatigue makes it more difficult for patients to talk about it. 'You can talk about your broken arm or your heart surgery and things like that and explain to your colleagues, your family or your friends what's happened to you but it's difficult to explain fatigue' (IBD Nurse, HCP11). In their attempt to understand how fatigue feels to people with IBD, HCPs compared it to their own feelings of tiredness. 'We are all tired. (...) What I would personally think fatigue is, is an extension, a worsening of that' (IBD Nurse, HCP1).

Study participants found it difficult to quantify fatigue and to know if it was a symptom specific to IBD, or at a similar level to the rest of the population. There was a lack of agreement between respondents regarding whether fatigue is more troublesome in the active stage of IBD (when other symptoms often dominate) or in remission.

Box 1. Steps of Colaizzi’s framework and the process of its utilisation:

- **Step 1:** The participants’ narratives were read to acquire a feeling for their ideas in order to understand them. Each transcript was read by three members of the team.
- **Step 2:** Significant words and statements directly relating to the phenomenon of fatigue were identified. Step 3: Meanings were formulated for each of the significant statement. All six researchers met and discussed the codes identified and consensus was reached by discussion. At this stage WCD compiled a list of the identified codes from the first 12 transcripts. From transcript 10 the codes were starting to repeat themselves, but two further transcripts were checked to make sure that no new codes were identified. This indicates that data saturation was achieved at transcript 12. In total 186 codes were created.
- **Step 4:** Identified codes were clustered into themes according to their meaning. Two researchers WCD and CN met to check and discuss the list of codes. Any overlapping or repetitious codes were combined, reducing the number of codes to 134. The codes were then arranged into three emerging themes. At this point all twenty transcripts were loaded into NVivo version 9 and WCD electronically coded the data.
- **Step 5:** All the resulting ideas were integrated into a detailed description of IBD fatigue. All six researchers met and discussed the themes and codes. Consensus was reached by discussion and resulted in identifying numerous sub-themes within each theme. The summary of the results were prepared by WCD (theme 1 and 2) and CN (theme 3).
- **Step 6:** The exhaustive description of IBD fatigue was reduced to an essential structure. The team communicated via email. All the team members read the data summary and provided comments on the first draft. This resulted in further reduction of the summary, while preserving the essence of the data.
- **Step 7:** All six researchers read the final data summary and compared this to the original interview transcripts to validate the study findings and made sure that all the data have been correctly and adequately represented.

Opinion about the incidence of fatigue in IBD was polarised; some respondents saw fatigue as one of the three or four top IBD symptoms and others as nothing more than a general tiredness and part of lifestyle. They perceived fatigue as subjective and not well understood by either practitioners or patients themselves. 'They [patients] might think I’m not as energetic as I was because I’m poorly, but might not associate it with extreme fatigue. (...) their energy levels are just zapped' (Dietitian, HCP17).

All twenty participants talked about the language that patients use to describe their feeling of fatigue and the challenge that HCPs face in gauging the meaning and the severity of the problem. Words recalled by respondents as used by patients when reporting fatigue to HCPs are...
summarised in Table 3. The terms seemed to refer to both the concept of fatigue (what fatigue is) and the impact that fatigue has on patients. The respondents were in agreement that patients tend to use generic, everyday language rather than the word ‘fatigue’.

The respondents reported using lay language when talking to patients, ‘I would talk to them mainly about tiredness, but I might write in the notes fatigue or lethargy. I think it matters what language we use for sure, I think if we don’t use the right language patients won’t understand what we mean’ (Gastroenterologist, HCP7). However at the same time the respondents recognised a problem with making the correct assessment of this very subjective symptom, and making the right judgement of its severity. ‘I would agree that language sometimes is a problem, because how would you measure fatigue?’ (IBD Nurse, HCP5). It was difficult to establish whether patients and HCPs are ‘speaking the same language’ when communicating about fatigue.

5.1.2. Sub-theme 2: contributors to fatigue

The respondents identified many factors contributing to IBD-related fatigue and to its severity, including: the severity of IBD, patient age, anaemia, medication, food restrictions and absorption problems, stress and emotions, pain, work and activity, and sleeping problems. The active stage of the disease, with inflammation and the symptoms that come with it such as diarrhoea were agreed by all as being key contributors to the presence and the severity of fatigue.

There was divided opinion on the presence of fatigue when IBD is in remission with some respondents stating that they wouldn’t ‘expect fatigue in a patient who was well controlled’ (Gastroenterologist, HCP10) and others contesting this: ‘I see people in remission and they absolutely report fatigue’ (Dietitian, HCP13).

Patients’ age, gender, lifestyle and work commitments were all perceived as factors associated with more frequent complaints of fatigue. ‘I think that people who are older do complain of it [fatigue] more. But those that are trying to work and feel quite unwell will also notice it affects them as well, so it’s quite a range, it probably does affect all of them, but I would say more the women who are in their 40’s, 50’s, 60’s’ (Dietitian, HCP17).

Anaemia, vitamin B12 and iron deficiency were frequently mentioned and were seen as obvious causes of fatigue. Fatigue was mentioned as a side effect of medication prescribed to treat IBD. Medication compliance was also raised as an issue in terms of controlling IBD activity and symptoms, including fatigue.

Food restrictions, unnecessary food avoidance and impaired nutrient absorption were seen as possible contributory factors. Patients with short bowel syndrome or an ileostomy were perceived as having additional absorption problems, leading to greater fatigue. Some patients were seen as restricting their diet unnecessarily while IBD is in remission, which can affect their tiredness. Clusters of factors with intrinsic relationships between them were identified as contributing to fatigue. These included poor long term nutrition and weight loss contributing to malnutrition, low grade depression with loss of appetite and low energy levels.

Some participants thought stress contributed to fatigue but others did not. The chronic nature of IBD and a longer period of living with the condition were identified as factors contributing to fatigue. Other factors such as pain, sleeping problems and sleep quality were also linked to fatigue. Respondents recognised that fatigue may also be related to co-morbidities, such as ‘rheumatoid arthritis, hypothyroidism or clinical depression’ (IBD Nurse, HCP1).

### Table 2

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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</thead>
<tbody>
<tr>
<td>1. Phenomenon of fatigue as perceived by HCPs</td>
<td>• Description of fatigue</td>
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<tr>
<td></td>
<td>• Contributors to fatigue</td>
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<td></td>
<td>• Prevalence and awareness of fatigue</td>
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<td>• Types of fatigue</td>
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<td></td>
<td>• Emotional (inner) impact</td>
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<td>• Private impact</td>
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<td>2. Impact of fatigue on patients’ lives as perceived by HCPs</td>
<td>• Public impact</td>
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<td></td>
<td>• Negative or fatalistic attitudes ‘don’t ask don’t tell’ approach</td>
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<td>• Healthcare systems as a barrier to fatigue management</td>
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<td></td>
<td>• Assessment of fatigue and assessing for factors associated with fatigue</td>
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<td></td>
<td>• Interventions and management of fatigue</td>
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<tr>
<td>3. Methods used by HCPs to deal with fatigue</td>
<td></td>
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</tbody>
</table>

### Table 3

<table>
<thead>
<tr>
<th>Fatigue described as concept</th>
<th>Fatigue described as impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients don’t use the word fatigue</td>
<td>Collapse, can’t do anything</td>
</tr>
<tr>
<td>Tired, very tired, tired all the time, extremely tired, tiredness, terrible</td>
<td>So tired can’t get their head off the pillow</td>
</tr>
<tr>
<td>Lethargy, very lethargy, really really really tired, deadly tired</td>
<td>Can’t get up in the morning</td>
</tr>
<tr>
<td>Lack of energy, low energy, loss of energy, having little energy, low energy levels</td>
<td>Being sleepy, falling asleep</td>
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<tr>
<td>Weak</td>
<td>Struggle to wake up</td>
</tr>
<tr>
<td>Exhausted, really exhausted, exhaustion</td>
<td>Plodding along</td>
</tr>
<tr>
<td>Fatigued</td>
<td>Can’t be bothered</td>
</tr>
<tr>
<td>Lethargy</td>
<td>Feeling down in myself, psychological words come into it</td>
</tr>
<tr>
<td>Knackered</td>
<td>Have got flu</td>
</tr>
<tr>
<td>Feeling unwell, feeling terrible, feeling under the weather</td>
<td>Hangover feeling, fatigue</td>
</tr>
<tr>
<td>General malaise</td>
<td>Hangover</td>
</tr>
<tr>
<td>Kind of anxious, very worried, tired and worried</td>
<td>Can’t put one foot in front of the other</td>
</tr>
<tr>
<td></td>
<td>Everything just seems like a huge effort</td>
</tr>
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5.1.3. Sub-theme 3: prevalence and awareness of fatigue

Participants were asked to estimate how many people with IBD experience fatigue. Varying prevalence of IBD fatigue was estimated by HCPs, ranging from 0 to 100%. Those who estimated fatigue prevalence at 0% felt that fatigue is not a feature of IBD and is not mentioned in medical textbooks. It was felt that if patients complain of fatigue it was due to acute inflammation and when treated, the fatigue will be resolved. Those who thought prevalence is low (10–20%), indicated that fatigue could be classed as general tiredness, common in modern society. 'If they're truly in remission, all their vitamin levels are normal, they're getting enough nutrition then I'd like to think their fatigue wouldn't be higher than generic populations' (Gastroenterologist, HCP7).

Participants who estimated higher levels of IBD fatigue felt that they saw patients with complex needs 'I would estimate that practically all of my patients suffer from fatigue because I get referred the extreme cases, the very complex patients. It's causing them to have lost a significant amount of weight and be severely depleted' (Dietitian, HCP9).

There was a lack of consensus on the relationship between fatigue and disease activity. Some thought that fatigue was more prominent while IBD was active, while some others thought that fatigue was more of an issue for patients while IBD was in remission. Some HCPs were not aware that fatigue was part of IBD 'I think before your study, before receiving the invitation to take part in your study I hadn't thought enough about it to be honest' (GP, HCP15). Others did not perceive fatigue to be one of the symptoms specific to IBD. 'The main 5 symptoms if I was teaching a medical student, fatigue wouldn't be one of them' (Gastroenterologist, HCP10), while some others thought that fatigue is starting to be recognised. 'I think that the new BSG [British Society of Gastroenterology] IBD standards talk about it [fatigue] but only very fleetingly really' (IBD Nurse, HCP4).

The HCPs often found fatigue to be complicated and difficult. 'If you have someone in clinical remission and you look at their colonoscopy and the histology and stuff it's all good, it's hard to understand why they're getting so fatigued if all their blood picture is all really normal, so I suppose that points you towards a psychological issue partly, poorly understood factors within the biochemistry or the levels of IBD that we don't know about and ways it affects the brain that we don't understand' (GP, HCP 15).

5.1.4. Sub-theme 4: types of fatigue

Participants referred to different types of fatigue, using a variety of ways of classifying these. Some referred to physical, mental and emotional fatigue. Some classified fatigue according to its severity as mild, moderate or severe; or fatigue was graded by its effect on the patient's activity. 'My grading is sort of activity indicated, so can they get up off the sofa and go down to the shops, can they get dressed' (Psychological Care, HCP19). A few saw fatigue as more temporary and intermittent depending on the time of the day and the activity: 'often they have it in the morning and it takes them a while to get up to speed during the day, but once they're up they're alright' (Hospital Pharmacist, HCP18).

Some participants found it hard to separate the emotional and psychological aspects from physical fatigue. 'You know, it sort of becomes a bit circular, if you're feeling so physically fatigued where everything's a lot of effort, then do you then feel much more negatively about being able to do anything, or does one influence the other so it then becomes very difficult to unravel' (Psychological Care, HCP19).

5.2. Theme 2: impact of fatigue on patients' lives as perceived by HCPs

5.2.1. Sub-theme 1: emotional (inner) impact

Most study participants perceived fatigue as having an impact on individuals' emotional well being. 'It's a self-blame. It's to do with not handling the condition properly and I've heard people say I'm lazy, I don't try hard enough, I should overcome this, I should battle through it, all these sorts of expressions' (Psychological Care, HCP2). The emotions frequently mentioned as related to fatigue were frustration, depression, low mood, concentration problems, lack of confidence, being out of control, low self-esteem and self-blame. 'I think fatigue in a way can be related to a certain corrosion of constantly dealing with something that you cannot really overcome' (Psychological Care, HCP16).

Patients were portrayed as 'normal people in abnormal circumstances' who may struggle to fully understand and accept the impact of IBD as a chronic condition, and to integrate the changes, including fatigue, into their lives. In some instances patients may need to fight to be listened to and to have their condition recognised.

5.2.2. Sub-theme 2: private impact

The private impacts of fatigue are mainly related to the patient's relationships in their role as a partner or a parent; and to other everyday activities such as looking after a house, cooking, hobbies, sport or socialising. 'They're really exhausted, and if they do manage to get to work they're absolutely exhausted when they come home from work and have absolutely no energy to do anything else, so their social life is kind of nonexistent. And yes with some people it affects everything really, and their relationships, because they're always tired' (IBD Nurse, HCP8). The only way for them to cope is to rely on help of others. 'I suppose they may be saying that they're relying on their partner or their children or other people to do things for them' (GP, HCP15).

Some mentioned the relationship between the HCPs and the patient. 'Probably they [patients] are confused about why they haven't got any IBD symptoms, but they're still feeling this terrible tiredness, and probably not very happy
with the health professionals who just tend to fob it off a lot of the time’ (IBD Nurse, HCP8).

5.2.3. Sub-theme 3: public impact
Participants identified work, employment and education as being affected by fatigue. Frequently mentioned was patients’ ability to work. ‘I would normally ask questions about what impact that [fatigue] was having on their sort of daily activities, get some idea about what they were able to do (...) were they just coming home a bit tired after work or were they not actually able to work (...) and there are others where it’s so profound they just can’t work or study’ (Gastroenterologist, HCP10). However in most instances despite being fatigued, patients would continue to work. Part-time employment was mentioned as an option for patients to be able to continue working. ‘I think there are some who’ve opted to take part time work instead of full time work to make their life more manageable’ (Gastroenterologist, HCP10). However people’s loss of income and job security through part-time employment and its wider implications were not fully considered during consultations with HCPs.

Trying to continue with employment or education was seen as a better long term option for the patient. ‘It [fatigue] just affects everything, they start to have time off from work so they’ll be having sick certificates from their GP and I think once that happens it’s a spiral, it sort of gets out of control then, and it’s trying to catch it before it gets that bad’ (IBD Nurse, HCP12).

A general lack of awareness of fatigue and its nature in the work environment were seen as problematic. ‘It’s [fatigue] something that can be confused with laziness in the workforce, so people are less likely to take it as serious [ly] as a broken arm or something which is clearly of limitation, so I think there needs to be some trust with your employer, and that of course is very variable’ (GP, HCP20).

5.3. Theme 3: methods used by HCPs to deal with fatigue

5.3.1. Sub-theme 1: negative or fatalistic attitudes: “don’t ask don’t tell” approach
Many participants mentioned professionals not asking about and in turn patients not volunteering information about fatigue. ‘Generally I think we don’t tend to talk too much about the fatigue, whether that’s right or wrong, but we don’t tend to, unless people bring it up with us, but I wonder whether we ought to really’ (IBD Nurse, HCP4).

Some saw patients as not very interested in fatigue. ‘It’s more the acute side of things that patients will want’ (IBD Nurse, HCP12). Most HCPs agreed that fatigue was not part of an initial IBD assessment. Although some routinely refer new patients to the Crohn’s and Colitis UK patient information pack and website, most seemed uncertain if fatigue is covered in this material.

Participants felt they don’t tackle fatigue directly. ‘I suppose I don’t really mention tiredness as a feature’ (IBD Nurse, HCP3). Some expressed guilt at not paying this more attention, ‘why don’t we, because we jolly well ought to’ (IBD Nurse, HCP4), while others appeared to avoid the issue of fatigue, and seldom raise it unless asked directly by a patient, and felt that patients seldom raise it. The issue of patients adjusting to and seeing fatigue as normal was mentioned often. ‘They [patients] have very good coping mechanisms so it becomes part of their norm I think but they don’t realise, or they forget what it feels like to have energy or be well, because they’ve been unwell or fatigued for such a long time’ (IBD Nurse, HCP11).

Some participants appeared reticent to raise the issue of fatigue with patients in the absence of any established or evidence based management options. ‘I think we don’t ask about it because quite frankly we don’t necessarily know what we can do about it, and you don’t really know what to advise’ (Gastroenterologist, HCP10). Others felt that that topic of fatigue was outside their comfort zone. ‘It lies squarely with us to bring the subject up really as part of the IBD in the same way as any part of the IBD. We’re happy to talk about bleeding, we’re happy to talk about diarrhoea and all sorts of things as being part of the IBD, once we get into something a bit sort of nebulous as fatigue, then we’re going a bit off from our comfort zone’ (IBD Nurse, HCP4).

Many participants were pessimistic about being able to help. ‘You like to be able to help patients don’t you and improve their symptoms, but that’s one aspect of their disease that I don’t think we can improve’ (IBD Nurse, HCP5).

Others felt that they should be attempting to change patients’ acceptance of fatigue as an inevitable part of IBD. ‘If patients are accepting chronic fatigue as part of their disease that to me is wrong, we should be trying to do something about that’ (Gastroenterologist, HCP10).

Most would investigate for causes of fatigue, but if nothing treatable was revealed, then it was felt that patients give up asking, ‘they often kind of accept that you’ve looked for a reason and there isn’t one’ (Hospital Pharmacist, HCP14).

Patients were perceived not to raise the issue of fatigue, or only mentioned it as an afterthought. ‘When you question them they say, oh yes I’m absolutely fine, but then almost as they’re going out the door it’s kind of, I’m still really, really, really tired’ (IBD Nurse, HCP8). Some felt that patients were relieved if the HCP acknowledged and raised the issue, and giving patients an opportunity to talk about fatigue was itself of value. ‘They almost breathe a sigh of relief because somebody has acknowledged it’ (Dietitian, HCP17). Others appeared to feel frustrated that they could not do more, ‘because there seems to be so little we can do about it, you feel very helpless really’ (IBD Nurse, HCP4).

5.3.2. Sub-theme 2: healthcare systems as a barrier to fatigue management
Financial constraints were repeatedly mentioned as a reason for not being able to offer an optimal service. This was especially common in relation to psychological services which some felt would help support people with fatigue. ‘On the whole it’s very restrictive, I spoke to one patient who had asked for counselling, and […] it’s a 13 month waiting list, […]well it’s a bit pointless isn’t it’ (IBD Nurse, HCP4).

Capacity and overstretched services were a consistent theme. ‘I think all resources are probably stretched beyond capacity at the moment anyway, even our gastroenterology clinics they’re over booked so the service itself is bulging at the seams’ (Dietitian, HCP13), and so taking IBD fatigue seriously in addition to current workload might be unrealistic.
This could be a source of frustration that the service is not ideal. 'They [patients] get vibes that myself or the doctor or whoever hasn’t got time for them to sit there and talk about how they are feeling in terms of fatigue for five or ten minutes. Which is, I know it’s not good, but it’s just unfortunately we don’t live in an ideal world and we’ve got a ridiculous, a huge amount of patients for the amount of staff we have’ (IBD Nurse, HCP8). There is also some pessimism about the way the multidisciplinary teams (MDT) are managed. 'Ideally within the MDT the patient should be managed from all these different perspectives so from the medical, the social, the psychological, the dietician, the nursing aspects, in reality at the moment I don’t see that that’s going to happen across the UK’ (Dietitian, HCP13).

5.3.3. Sub-theme 3: assessment of fatigue and factors associated with fatigue

All interviewees agreed on the importance of investigating for active disease and getting this under control. There was an individualised approach as to which investigations are warranted rather than use of any guidelines. 'Camera, having a look, checking sigmoidoscopy, maybe if it’s a Crohn’s patient then we’d be looking at say a faecal calprotectin to see if there’s any sign of activity there. It varies; it depends on the patient really’ (IBD Nurse, HCP11). ‘I think one has to concentrate on the diarrhoea first rather than the fatigue, if you can fix the diarrhoea, the fatigue may well get better on its own’ (Gastroenterologist, HCP7).

Anaemia or low iron levels were also mentioned by most respondents, nearly all of whom would test haemoglobin and ferritin levels. Beyond that, a wide variety of possible blood and other tests were mentioned, but none consistently. Many participants emphasised that multiple lines of investigation might be needed. ‘I think it’s often multifactorial isn’t it, I don’t think you can say there’s one thing, I think you need to look at the simple things first – are they anaemic, do they have any vitamin deficiency, and then are there any signs of active inflammatory disease and correct those things. (…) And then we would need to look at other causes of fatigue, so things perhaps that are non-IBD associated with fatigue – I’ve never had any kind of guidance on how to assess fatigue’ (IBD Nurse, HCP11). No interviewee was using any formal method (e.g. a fatigue scale) to assess the symptom of fatigue. Many HCPs described an ‘ideal world’ with more time and resources, where fatigue could be better managed. ‘In an ideal world it would be nice to have a fatigue clinic’ (IBD Nurse, HCP11).

There were mixed feelings as to whether a fatigue scale or an algorithm would be useful; some HCPs felt that ‘having some sort of objective measure would be brilliant’ (IBD Nurse, HCP4), while others feared that there were already too many assessment tools used in IBD and that patients would not be willing to fill in yet another questionnaire. ‘I just think the more bits of paper we have, the less often they’ll get used’ (IBD Nurse, HCP5). If the patient was otherwise well, some HCPs would do nothing further to investigate fatigue. ‘I don’t think I did anything else because his other symptoms were OK’ (IBD Nurse, HCP3). If test results are normal many were at a loss to know how to help fatigue, ‘you just sort of feel what on earth can I do now?’ (IBD Nurse, HCP4).

5.3.4. Sub-theme 4: interventions and management of fatigue

Participants identified various interventions for managing fatigue and its causes. Medical interventions such as treating active disease, anaemia or low iron levels and vitamin deficiencies were seen as important for directly or indirectly improving fatigue. Oral iron was often mentioned as poorly tolerated in IBD patients and intravenous (IV) iron seemed to be popular where the service was available. Biological medication was mentioned as helpful for fatigue, ‘I’d say probably the biologics is the most noticeable difference from a fatigue point of view’ (IBD Nurse, HCP8); although none thought that this medication would ever be prescribed to patients just for fatigue. Beyond this there was little consensus and few suggestions on how HCPs manage fatigue.

Many expressed a desire for better education and/or guidance on IBD fatigue management, ‘It would be good to have a clear guidance from specialists’ (GP, HCP15). There was a lot of emphasis on teaching patients with fatigue to self-manage. Participants were in agreement that having a website, good quality information leaflets, management strategies and tips would be helpful for patients. Currently, many HCPs seem to give vague, imprecise and contradictory advice, such as: rest more or exercise more, pace yourself or build up gradually. There was very little specific, practical advice. ‘It’s an educated guess I would say, I just say start off gently’ (IBD Nurse, HCP8). Participants wanted more education about fatigue. ‘I probably don’t know enough about it [fatigue]. (…) I think our education is really important because if we don’t know what’s happening, we can’t educate patients, and I think that’s the current situation. (…) What interventions actually work and then we can decide who’s best placed to offer those’ (IBD Nurse, HCP8).

Education of patients and patient-self management was raised by many; however it was felt that not all patients want to engage with information and self help. ‘I think it probably splits 50-50, some people are really, really, really well informed, and […] very motivated and have read up on things on the internet, and taken on board everything they’ve been advised through their doctors and consultants, and other people are fairly detached from the condition and maybe don’t really want to know, which may reflect that they don’t really want to know they’ve got the condition’ (GP, HCP15).

There was consensus that managing fatigue should be a multi-disciplinary effort, but with little idea of who should do what. HCPs reported referring patients to each other, but did not articulate a clear objective or even an idea of what a colleague might be able to offer for fatigue. There was a sense of patients being referred around in circles with nobody taking responsibility for fatigue. GPs were often mentioned by hospital-based HCPs as the best person to manage fatigue, but they had no specific expectation
of what GPs could do. ‘There’s no pathway for patients because it is all very individualised care. So I think we wouldn’t necessarily expect GPs to know a lot about IBD generally. I don’t know what they know about fatigue, they would probably know more about fatigue than we do because fatigue happens in a lot of other conditions’ (IBD Nurse, HCP1). GPs were often seen as gatekeepers for psychological services and in some places for community-delivered IV iron. Many participants wanted clear care pathways for fatigue. ‘To have some good pathways that work very well, that we can refer patients on to appropriate people, that’s number one’ (IBD Nurse, HCP6).

6. Discussion

This is the first study to explore HCPs’ views of IBD fatigue. HCPs find it difficult to conceptualise fatigue. They demonstrate a varied level of knowledge and awareness of IBD fatigue, with all of the study participants having problems understanding fatigue and reporting it to be a subjective, complex concept. It is difficult for HCPs to know how fatigue feels to patients, and how to quantify its severity and impact. Fatigue is one of the most common symptoms reported in IBD; however it is poorly understood and requires further clarification and development. In order to make sense of fatigue, HCPs compared their own level and experience of tiredness. Some questioned if fatigue is specific to IBD, or if patients are reporting ‘normal tiredness’ related to everyday activities. There was a polarised opinion on the prevalence of IBD fatigue, estimates varying from 0 to 100%. Reported fatigue prevalence in IBD in remission ranges from 22 to 41%, however in active disease fatigue ranges from 60 to 86%; however these ranges do not seem to be accepted by HCPs.

HCPs referred to many different characteristics of fatigue e.g. types, severity, pattern, acute (in relapse) or chronic (in remission) fatigue. The classification of fatigue used by HCPs was ad hoc and unsystematic. This echoes the findings of a recent literature review which identified many challenges related to a lack of clarity on the classification of fatigue and its definition.

The language used to communicate fatigue was recognised to be important, as it is the only means to report fatigue, but there are challenges due to the different meanings and the use of different terms by patients and HCPs. It was recognised that lay language should be used to communicate with patients. In a previous study people experiencing IBD fatigue also reported fatigue as difficult to define and categorise, with frequent use of metaphors and similes to reflect and describe their experience.

Numerous physical, psychological/emotional and social factors associated with fatigue were identified. Physical factors e.g. disease activity, anaemia, ferritin level, vitamin deficiency, were most frequently assessed and acted on. However none of the factors were assessed in any systematic manner and there was no evidence of any systematic approach to rectify the problem. To date the pathogenic process of fatigue is unclear. In other chronic conditions where fatigue is frequently reported (e.g. cancer, multiple sclerosis and rheumatoid arthritis), the specific mechanisms for development of fatigue also need further investigation. In cancer patients, specific clinical practice guidelines on assessment and management of fatigue have been developed.

It was apparent that HCPs have a limited understanding of how fatigue impacts on lives of people with IBD, as reported by patients. This may act as a barrier to patient assessment. IBD patients report that their complaints of fatigue were ignored and that they felt unsupported by HCPs. It appears that some HCPs adopt the ‘don’t ask don’t tell’ approach to IBD fatigue. Avoiding the topic of fatigue could be explained by lack of understanding of fatigue, or because fatigue is not part of the initial discussion with newly diagnosed patients. Fatigue has not been named as one of the IBD symptoms by European guidelines for CD or UC published in 2006 and 2008 respectively; however more recent medical and nursing publications have already mentioned fatigue as one of the symptoms of IBD.

Some patients report that they did not know that fatigue is a symptom of IBD, and when experienced, it causes them psychological distress, possibly delaying reporting to HCPs. Fatigue becomes part of the norm for the patient, and their new life with IBD. It is important for HCPs to acknowledge fatigue, as this may encourage patients to talk about it as a legitimate problem.

Some HCPs reported being reticent to assess fatigue as there are no tested management options. There is a need to break with the traditional view ‘no inflammation therefore no fatigue’, to allow for a broader approach to assessment for factors related to fatigue. Currently interventions used to manage fatigue are largely restricted to dealing with active inflammation and treatment of anaemia. There is a need for evidence based interventions addressing a broad spectrum of factors associated with fatigue, however at present that evidence is lacking.

A combination of barriers to care for fatigue were raised by HCPs, such as a lack of information regarding the concept of fatigue, fatigue assessment and its management; financial and resource issues with overstretched healthcare services not being able to accommodate ‘new’ problems, leaving HCPs feeling helpless to help patients with fatigue. There is a need for an effective, collaborative approach between MDT members to managing fatigue.

Involvement of MDT members was seen as very important. There seems to be a need for care to be coordinated, with clearly defined referral pathways. IBD nurses and specialist dietitians seem to be well positioned to coordinate IBD fatigue services, but additional resources would need to be identified. GPs have been seen as ‘gate keepers’ to other services e.g. psychological referrals; however GPs need clear guidelines on what care is required for an individual patient.

7. Limitations of the study

Qualitative studies typically use a small sample size, aiming for breadth and depth on a topic where little is known. It does not aim to be numerically representative of the studied population, but rather reflects the range of professionals involved in IBD care. The data only reflects the experience and views held by
the participants and the study is UK based. Due to recruitment difficulties the final composition of the group was less balanced than originally intended, with IBD nurses dominating the group.

8. Conclusion

Although fatigue is one of the symptoms most frequently reported by IBD patients, it is poorly understood by HCPs, who find fatigue challenging and frustrating. Systematic and structured assessment and management of this distressing symptom should include physical, nutritional and psychological aspects, and HCPs should communicate with each other about care for each individual patient. Patients should receive clear information about possible IBD symptoms such as fatigue. There is a need for an assessment framework and for intervention strategies to be tested. It is essential for MDT members to be involved in planning and managing coordinated care of patients reporting fatigue in IBD.

Conflict of interest

WCD, IN, FB and CN have received funding from Crohn’s & Colitis UK to conduct the study. CN has been an Honorary Nurse Adviser to the Board of Trustees, Crohn’s and Colitis UK, and MD and HT are employees of Crohn’s and Colitis UK.

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