

Abstract:

Background: Fatigue is a frequently reported symptom of inflammatory bowel disease (IBD), having a negative impact on Health-Related Quality of Life (HRQoL). Patients' experiences of this have not been researched in IBD.

Methods: Semi-structured interviews were conducted with adults with Crohn's Disease from out-patient clinics in the United Kingdom. Interviews were audio-recorded and transcribed verbatim, then analysed using thematic analysis.

Results: Fourteen participant interviews were conducted. Three key themes were identified: 1) 'The new normal' established through adaptation and acceptance; 2) 'Energy as a resource' describing attempts to better manage fatigue through planning and prioritising tasks; 3) 'Keeping healthy' encompasses participants beliefs that 'good health' allows better management of fatigue.

Conclusion: Participants establish a 'new' normality, through maintaining the same or similar level of employment/education activities. However, this is often at the expense of social activities. Further research is required to explore patient led self-management interventions in IBD fatigue.

Keywords: Fatigue, Health Related Quality of Life, Interview, Crohn's Disease, Inflammatory Bowel Disease.

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Introduction

Fatigue related to Inflammatory Bowel Disease (IBD) and other long term conditions (LTCs) is defined as an 'extreme and persistent sense of tiredness, weakness or exhaustion'(Dittner, Wessely and Brown, 2004) which can be physical, mental or both and is not easily resolved by sleep or rest (Dittner, Wessely and Brown, 2004; Arnett and Clark, 2012). The international classification of diseases code presents fatigue as an assortment of physical, cognitive and emotional symptoms affecting undertaking of daily tasks (Haney, E., Smith, B., McDonagh, M., Pappas, M., Daeges, M., Wasson, N. and Nelson, 2015).

Prevalence of IBD fatigue is reported as 41-48% for patients in remission and as high as 71-86% for patients with active disease (Czuber-Dochan, Ream and Norton, 2013). IBD fatigue is one of the top 5 research priorities highlighted by the Nurses European Crohn's and Colitis Organisation (N-ECCO), and a top 10 research priority identified through the James Lind alliance (Mowat *et al.*, 2011; Dibley *et al.*, 2017; Hart *et al.*, 2017). Recently, the symptom of fatigue in LTCs has received greater attention as part of overall Health Related Quality of Life (HRQoL) (Swain, 2000). However, to date, there has been no specific consideration of the impact of IBD fatigue on an individual's HRQoL.

The aim of this interview study is to explore patient experiences of IBD fatigue and its impact on HRQoL. Undertaking this work will highlight areas for future research focus, by emphasising areas of daily life that are most impacted by IBD fatigue, and have the most negative impact on HRQoL. This will allow us to better understand and design interventions to improve the lives of people living with IBD.

Health Related Quality of Life

Increasing life expectancy has highlighted the need for other measures of health, capturing the quality of the years someone lives. IBD is incurable and, owing to the physical and psychological impact of the disease, significantly reduces patients HRQoL (Huppertz-Hauss

et al., 2015). The concept of quality of life (QoL) is not a new one, in 1995 the World Health Organisation (WHO) recognised the importance of improving peoples QoL('The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization', 1995). When QoL is considered in the context of health and disease, it is commonly referred to as HRQoL to differentiate from other aspects of QoL. Health is a multi-dimensional concept, HRQoL is also multidimensional and incorporates areas related to physical, mental and social functioning(Ferrans, 2005). HRQoL goes beyond the direct measures of health and focuses on the QoL consequences of health status. HRQoL represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient. It encompasses several dimensions of life, including physical functioning, psychosocial functioning, role functioning, mental health and general health perceptions. HRQoL is determined by socio-demographic, clinical and psychological and treatment-related determinants (Cohen, 2002; Peyrin-Biroulet, 2010; Diener and Seligman, 2018). Clinicians and public health officials use HRQoL to measure the impact of chronic illness. Additionally National Institutes of Health, e.g. cancer institute, have included evaluation and improvement of HRQoL as a public health priority.(Diener and Seligman, 2018)

This is the first interview study of its kind to specifically focus on the impact of IBD fatigue on the HRQoL of adults living with IBD Fatigue. This work will compliment previous and ongoing work in similar areas, and will highlight areas of focus for future research in the understanding of IBD fatigue.

Methods

A qualitative semi-structured interview study utilising thematic analysis (Braun and Clarke, 2006) was chosen.

Interviews are amongst the most accustomed way of collecting qualitative data. Interviews are best suited to collecting information regarding peoples understanding, perceptions and

periences.(DiCicco-Bloom and Crabtree, 2006; Flick, 2009) Interviews were organised around a set of pre-determined, open ended, questions, with other questions emerging from the dialogue of the interview. Interviews were conducted in this manner to gain greater clarification through exploration of detailed descriptions of the studies topic from participants (Miller, William L. Crabtree, 1992). Reflective questioning was used to allow deviation from the interview schedule to pursue topics guided by the participants (Lee and Barnett, 1994; Agee, 2009).

All interviews were conducted by the same researcher (SR). This was an important step in reducing the risk of bias. Interviews were digitally audio recorded and later transcribed verbatim by the same author. To maintain confidentiality, with no loss of contextual data, information containing identifiable data, such as names of individuals or places, were replaced with general or explanatory terms in square brackets (Wiles *et al.*, 2007). Given the substantial dataset generated from the study, coding and organisation of the data was conducted within NVivo 12 software. Transcripts were coded line-by-line, assigning sections of data to a code which summarised the material according to what each extract revealed.

The researchers assumed a critical realist position(Nightingale and Cromby, 1999) and recognising the research team as an active part of the research process, aware of the importance of considering the influence of individual experiences (including contact with participants and patients) in the shaping of the study and interpretation of the results(Bhaskar, 2013). This was chosen as the epistemological stance as it best fit the exploration of participant beliefs and experiences in constructing the understanding of the impact of IBD fatigue on the HRQoL of adults with IBD. The distinctive feature of this form of realism is the denial that there is objective or certain knowledge of the world, and the researcher should accept the possibility of alternative valid accounts of any phenomenon.

Sample size and recruitment strategy

Using guidance from literature regarding qualitative sampling and previous research considering similar cohorts, an initial sample size of 20 participants was chosen (J. Ritchie and Lewis, 2003; Silverman, 2013). The adequacy of the final sample size was continually assessed during the data collection process, when a point of 'data saturation' was established the study was closed.

Access to participants was facilitated through an existing working relationship with National Institute of Health Research Nottingham Biomedical Research Centre (NIHR Nottingham BRC). The study recruited 14 participants in total. Purposive sampling was used, seeking to maximise the depth of the data collected (Miller, William L. Crabtree, 1992). Only participants with a confirmed diagnosis of IBD, by endoscopy, histology or MRI, and described as fatigued using the Multidimensional Fatigue Index (MFI-20) (Gentile *et al.*, 2003) questionnaire, were approached. The MFI-20 was used to confirm the presence of fatigue, rather than the IBD fatigue scale (Czuber-Dochan *et al.*, 2014) as the MFI-20 has a clinically validated cut off point for diagnosing fatigue, where the IBD fatigue scale does not. The IBD fatigue scale was used to help guide the interview process by highlighting the areas of their daily life that participants may have felt the most functional restrictions due to IBD fatigue (Czuber-Dochan *et al.*, 2014). Those participants who met the inclusion criteria and provided a written consent, were interviewed at a convenient time for them.

Eligibility criteria

Inclusion and exclusion criteria are detailed in Table 1. It was decided that the study sample, would consist solely of patients with CD. This decision was based on higher prevalence of fatigue in CD than in UC patients, making recruitment more feasible (Hashash, Benhayon, Szigethy, Rivers, 2012; Gajendran *et al.*, 2018; Hashash *et al.*, 2018).

Data Collection

Early introduction of the study information ensured that the participant was aware of the purpose and level of their involvement. Verbal consent was obtained in order to book the time and place for the interviews. Valid informed consent was received by the lead author on the day of interview, prior to undertaking the interview.

When beginning the interview, it was important to establish background information to contextualise the rest of the interview (Blandford, 2013). This enables the researcher to access a deeper understanding of the data, and also guide the interview and interview questions in order to obtain richer data (Blandford, 2013).

During this phase, broad open-ended questions were used to help the participant establish confidence. This helps the participant 'settle into' the interview, reducing feelings of anxiety and increasing their willingness to share personal details and detailed responses ('A Four-part Introduction to the Interview: Introducing the Interview; Society, Sociology and the Interview; Anthropology and the Interview; Anthropology and the Interview—Edited', 2014). The themes of interest shaped the interview, derived from the IBD fatigue scale and the participants responses to questions, meaning that the direction and content of the interview was dictated by those topics that arose and those deemed interesting and relevant by the interviewer (Jane. Ritchie and Lewis, 2003). This enables thorough exploration of topics and allows the interviewee to provide detailed, in depth responses to questions that are also sensitive to the nature and depth of the information willing to be disclosed by the participant (Booth and Booth, 1994). Continuity of theme is important as participants are likely to be thinking in a focused way about topics they don't naturally consider in as much depth. During the core phase of interviewing a technique used to help with recall, the critical incident technique (Flanagan, 1954), was used to extract details of specific incident or examples. This involved asking people to focus on the details of specific incidents rather than generalisations and allowed the collection of much more detailed responses than might have been given with open ended questioning.

In the lead up to the end of the interview it was clearly signalled to the participant by stating “we are coming to the end of the interview now” during the conversation. This allowed participants to wrap up conversation, making any final statements. After the close of the interview the participants were thanked for their time and contributions. Interviews were digitally recorded, and later transcribed by the lead author. Careful consideration was given to the placement of the recorder and the environment that the interview was conducted in order to reduce such issues as poor recording quality and background noise (Bailey, 2008).

Data Analysis

Thematic analysis (TA) was considered a suitable method to gain an overall exploratory understanding of the pattern of experience in this population.

Traditionally TA has been seen as a process performed within major analytic traditions such as Grounded theory (Boyatzis, 1998; Ryan and Bernard, 2000), however more recent work, particularly in the field of psychology, have framed TA as a method in its own right (Braun and Clarke, 2006). In contrast to other exploratory methods such as interpretive phenomenology, which follows an in-depth, idiographic approach, TA allows greater flexibility to include participants from a somewhat heterogeneous background (Braun and Clarke, 2014). This was considered important for the present research, seeking to gain an overall insight into the experience within the IBD population rather than a particular subgroup. An inductive, semantic TA was designed, in accordance with the research question and the researcher’s epistemological position. An inductive approach means the themes identified will be strongly linked to the data, without trying to fit into pre-existing coding frame (Patton and Patton, 2002).

Data collection and analysis occurred in parallel, allowing the adequacy of the final sample size to be continually assessed during the data collection process, when a point of ‘data

saturation' was established this was discussed with the principal investigator of the study and recruitment to the interview study was closed.

Generally it is considered that saturation is the point at which additional data do not lead to any new emergent codes or themes (Birks, Mills and ~s, no date; Urquhart, 2013; Given, 2016). The concept of data saturation originates in grounded theory (Charmaz, 2000), it is now used across a range of approaches in qualitative research. Some researchers claim that a failure to reach saturation has a negative impact on the quality of the research (Recommended Apa Citation Fusch and Ness, 2015). Saturation is the most commonly billed measure of qualitative rigour offered by authors (Morse *et al.*, 2002; Guest, Bunce and Johnson, 2006; Morse, 2015).

Results

Interviews took place between September 2018 - July 2019. Interview duration averaged 54 minutes, with a range of 37 - 62 minutes.

Sample Characteristics

Fourteen participants were recruited, of which nine (64%) were females. All participants identified themselves as of a 'White British' ethnic origin. Respondents were an average of 37.3 years of age, (SD ± 13.5). Participants reported they experienced symptoms of IBD fatigue for an average of 10.9 years (SD ± 4.6) All participants were considered as experiencing fatigue using the MFI-20 questionnaire as part of the inclusion criteria (Beck *et al.*, 2013). Using the IBD fatigue scale (Czuber-Dochan *et al.*, 2014), 11 out of 14 participants reported that fatigue was constant and three reported Intermittent fatigue. Further sample demographics are shown in Table 2.

Themes

Data analysis resulted in identifying three main themes and eight sub-themes (Figure 1).

Theme 1- The new normal

Participants described how living with IBD fatigue had become 'normal' for them. A sense of a 'new normal' was established by some. One participant reported that through undertaking the interview study it *"made me realise how much [IBD fatigue] does affect me, and how normal it has become"* (IT06, Male, 27 years of age).

Acceptance

Participants described and defined IBD fatigue in their own words. They described differences between tiredness and fatigue; *"fatigue is much worse, like a whole-body lack of energy, tiredness can pass but fatigue sticks around no matter what I do"* (IT08, M, 26).

Definitions used language to describe the physical feelings of fatigue; *"Like I am wearing a heavy coat all of the time"* (IT14, F, 25) and *"I feel like my bones are heavy and I am tired all over"* (IT08, M, 26). Participants also described impact on mental feelings of fatigue; *"fatigue is a blanket that covers every kind of thing I try and do"* (IT04, F, 34). Participants were keen to distinguish the differences between 'physical' and 'mental' fatigue: *"I think I am just much better at managing my physical symptoms and maybe just get on with my mental fatigue"* (IT03, F, 30).

IBD fatigue was 'accepted' by some participants, and its impact on their ability to undertake daily tasks at home, *"I have just come to accept it, it is a way of life now"* (IT13, F, 27), and at work *"there's no question, I definitely can't do as much as I used to do"* (IT02, F, 45).

Motivation to keep up with the same daily activities as before IBD fatigue and in comparison, to those without fatigue, was important to participants; *"I just don't let it get on top of me. It's the motivation thing, so long as I keep going, embrace the fact that things will take a bit more effort for me to do the same things as other people do"* (IT03, F, 30).

Adaptation

The most predominant adaptation discussed was making plans; *“if I plan and use my day wisely it means I have enough energy left at the end of the day for more fun things”* (IT11, M, 51). Making plans allowed participants to take control of their day-to-day life; *“I can take control of my workday, manage my day better”* (IT11, M, 51).

Adaptation comes about from previous maladaptive techniques such as all or nothing behaviours; *“I used to think about what I wanted or needed to do the most and then I would do that and hope that I had enough energy left to do the rest, if I didn’t, I would cancel plans or call in sick to work, I did my best to stop doing that as that’s unhealthy behaviour”* (IT13, F, 27). Some participants acknowledged that utilising adaptive behaviours requires greater effort *“[fatigue] makes things harder to do, it takes more effort, both in the actually doing the thing, like going out or making dinner, but it takes times to plan it too. I have to put in a lot of effort planning”* (IT03, F, 30). Adaptation involved establishing new limits encompassing activity at home, work and leisure activities; *“I plan to do enough with my day so that I am tired, but not exhausted, I know my limits”* (IT09, F, 44).

Social impact

IBD fatigue appears to have a meaningfully negative impact on social interactions. *“It has the biggest impact on my social life”* (IT04, F, 34). One participant reported that they felt interacting socially actually alleviated feelings of fatigue *“laughing and joking and seeing my friends helps me feel better”* (IT08, M, 26).

Participants state that Intimate relationships are adversely impacted on by IBD fatigue, as fatigue can lead to extended periods of little or no intimate relations with partners *“when I’m really worn out it can be weeks where we don’t do anything”* (IT06, M, 26). Weekly routines, designed to prioritise work, can de-prioritise intimacy *“we don’t really spend any time together in the bedroom, except for weekends”* (IT05, F, 25).

Understanding of IBD fatigue by family, friends and colleagues was important to participants. Most participants reported having good social support, however understanding of the disease was often lacking; *"I think that they understand that I have an illness that can mean I can't always do things with them, but I don't think that they actually understand the disease."* (IT10, M, 49). Not all participants reported a lack of understanding. One participant reported their partner's understanding and appreciation of the impact of IBD fatigue *"has contributed to us being close"* (IT07, M, 52). Support of colleagues has been discussed in the adaptations sub-theme, but it was also reported as a way of alleviating fears of social stigma in the workplace, *"I felt I was able to say "I don't feel like I can do that", and I didn't get judged or laughed at"* (IT09, F, 44).

Participants discussed worries related to how they would be perceived by others, *"I worry about looking like I am always ill, like the flaky friend who is constantly cancelling plans"* (IT08, M, 26). Participants often based this feeling on comparison to others, *"I feel like I get much more tired, more quickly, than those around me, and it can be annoying and sometimes embarrassing"* (IT05, F, 25). This was frequently related to the workplace *"I don't want people to think any less of me, like I can't do my job, like it is something that stops me from being able to do things like other people can"* (IT11, M, 51). This could lead to lessened feelings of self-worth, lowered self-esteem and reduced motivation to maintain social relationships and interactions, even though participants acknowledged that these are important to them.

Theme 2- Energy as a resource

Participants referred to energy as a commodity, describing how energy levels could be managed through prioritisation and planning of tasks. This belief might be a way of contextualising and understanding fatigue, and may also be way of better communicating fatigue to others. A prominent feature of most interviews was that participants believed that they were constantly at a 'deficit' in terms of levels of energy; *"I feel like I start off with a*

negative balance anyway, like I wake up in the morning and I already don't have enough energy to make it through the day before I have even done anything" (IT05, F, 25).

Energy use

Energy use was discussed through the allocation of observed amounts of energy to prioritised and planned tasks; *"every task I do has to be weighed up in terms of how much time and energy it will take to complete it"* (IT11, M, 51). Often employment or studying was prioritised over other activities; *"I give all I have got at work, which leaves me really tired and with no energy left for outside of work things"* (IT06, M, 27). Only one participant reported *"I try and strike a balance between my work life and home life"* (IT11, M, 51).

All or nothing behaviours were prevalent throughout the interviews; *"By the time I get home, I don't have any energy left to do anything around the house"* (IT05, F, 25). This type of behaviour was often weighed against the need for energy for ongoing daily tasks, or activity over subsequent days; *"I start out at a deficit, if I then go and blow all of the energy I have on doing all of the washing and hoovering and cleaning in one go, then I won't be much good for the rest of the day, or even the day after"* (IT13, F, 27). The abundance of all or nothing behaviours suggests that there is a lack of awareness of fatigue management techniques, such as poor task prioritisation or lack of motivation.

Energy conservation

'Making plans' was integral to establishing a sense of 'normality'; *"I plan what I need to do each day and make sure I have enough energy to be able to do all the things I want to do"* (IT08, M, 26). A primary management technique employed was to introduce more rest into daily routine; *"I just have to make sure that I have to rest, sleep, to make sure I have time to catch up on my sleep and have the energy to go to work the next and the next day"* (IT12, F, 51). However, most participants agreed that even after rest they were unable to feel well rested; *"incapable of catching up on the energy I am using up"* (IT03, F, 30). Energy

conservation techniques included tendency to 'sacrifice' the undertaking of an activity; *"I do just write things off as too much effort"* (IT06, M, 27).

Theme 3- Keeping healthy

General health

Participants reported that having a good general health was beneficial for them as it helped them to overcome the feelings of fatigue; *"I think maybe I have a good level of general health, so I have a better ability to be able to compensate for fatigue"* (IT09, F, 44). Most participants reported that they were able to maintain a good level of personal care even when experiencing high levels of IBD fatigue. However, two participants reported that high levels of IBD fatigue would impact on their choices regarding personal care; *"I'll skip having a shower and go straight to bed and shower the next day if it's really bad"* (IT10, M, 49). As only two participants reported this, it could be suggested that for most people, IBD fatigue does not have an impact on personal or self-care though this issue might be underreported due to embarrassment.

Nutrition

Participants reported that at times, food preparation was impaired by their high levels of fatigue; *"I don't want to use the last of my energy on cooking us something to then not be able to eat it and enjoy it. If it takes longer than 30 minutes to cook, then I'm not going to make it"* (IT03, F, 30). Conversely, the majority of participants reported that they ensured they maintained a healthy diet as they believed this would help them reduce levels of IBD fatigue and improve the ability to cope with it.

Physical activity

Physical activity was considered important in being better able to better overcome feelings of IBD fatigue; “ *I think by keeping up regular exercise it keeps me healthy, making it easier to get through that heavy fatigue feeling*” (IT13, F, 27).

Participants reported that physical activity reduced levels of IBD fatigue; “*I can sometimes feel like I have a little more energy, like I have managed to access some reserves in my body, sometimes that helps*” (IT05, F, 25). One participant reported that undertaking physical activity gave them a sense of achievement; “*When I go to the gym I do feel better in myself, like I have achieved something*” (IT04, F, 34). This sense of achievement could encourage feelings of accomplishment and boost motivation. Participants reported that keeping up a level of physical activity/exercise was something that they included in their daily planning; “*I like to go to the gym. I try and go at least three times a week....For me it is just as important to stay active as it is to get lots of rest. It is a momentum thing*” (IT03, F, 30).

Discussion

Impact of IBD fatigue on HRQoL extends beyond the impact upon the individual as a feeling or experience, but instead, impacts the structure of their daily lives and every decision made (Kalafateli *et al.*, 2013). Since many of those diagnosed with IBD are young, the impact of fatigue on an individual's education, personal and professional life may be greater in IBD than in other LTCs (Lesage *et al.*, 2011; Floyd *et al.*, 2015).

Throughout the interview study participants reported strategies used to better manage daily life with fatigue. These strategies often incorporated planning and prioritisation of tasks in order to coordinate utilisation of energy and control energy levels. Through task prioritisation favouring work and education, participants reported that they would often miss out on social interactions and reduce or remove leisure activities from their daily life.

The individuals' ability to deal with stress and cope with IBD fatigue has been shown to have an impact on HRQoL. 'Normalising behaviours' were described during the interview study in

terms of the participants incorporating fatigue management techniques into their daily lives in order to reduce the negative impact that fatigue has on daily functioning. Those with high levels of acceptance, 'good' ways of coping and adapting to life with IBD, have better HRQoL (Tanaka and Kazuma, 2005; Bol *et al.*, 2010; Lesley A Graff *et al.*, 2011; Lesley A. Graff *et al.*, 2011). A variety of different words were used to describe fatigue such as 'tiredness', being 'worn out' and 'run out of energy'. The acceptance of illness is a significant factor affecting the level of HRQoL in patients with LTCs, such as cancer (Chabowski *et al.*, 2017), Rheumatoid Arthritis (RA)(Kostova, Caiata-Zufferey and Schulz, 2014) and heart disease (Obiego *et al.*, 2017).

Self-motivated acceptance processes relate to people's perceptions of independence and dependence, as well as feelings of helplessness, and efficacy in coping with chronic symptoms (Pollock, 1987; Gignac, Cott and Badley, 2000; Megari, 2013). If individuals self-manage their chronic illness successfully, it is likely that their HRQoL will be enhanced (Weinert, Cudney and Spring, 2008). It is well reported that individuals with IBD have higher HRQoL when they feel they have some control over their symptoms (Sainsbury and Heatley, 2005; Woodward *et al.*, 2016; Skrautvol and Naden, 2017). Self-management techniques instil a sense of responsibility upon the individual to take ownership over their own health and promote a positive perception of self (Harper *et al.*, 1998; Bishop, 2005; *Living well with chronic illness: A call for public health action*, 2011). Individuals who display acceptance by improving their coping behaviours through therapy, such as cognitive behavioural therapy, have been shown to have better HRQoL (Fukuda *et al.*, 1994; Power *et al.*, 2008; Repping-Wuts *et al.*, 2008; Micol Artom *et al.*, 2017; Luo *et al.*, 2018).

Feelings of fulfilment are determined by levels of satisfaction in specific areas of an individual's life (Pavot and Diener, 1993). How individuals with LTCs perceive societal demands can lead to feelings of stigmatisation. Stigma can negatively impact an individuals' personal identity, social life and economic opportunities, in turn contributing to sense of unfulfillment (Joachim and Acorn, 2000; Ablon, 2002). Through task prioritisation, favouring

work and education, participants reported that they would often miss out on social interactions. This has a negative impact on HRQoL. Patients with IBD have been shown to feel like IBD fatigue stops them from achieving what they perceive as their full potential (De Rooy *et al.*, 2004). Some of the study participants discussed their feeling relating to feelings of isolation and reliance on family members leading to feeling like a burden. Patients worry that their fatigue restricts not only their own, but also their families social activities (Woodward *et al.*, 2016).

Acceptance of IBD and using effective coping strategies improve levels of HRQoL. Study participants discussed their sense of acceptance in terms of how they manage their daily life. Negative attitude and ineffective strategies, such as all or nothing behaviours, worsens HRQoL (Sainsbury and Heatley, 2005; Tanaka and Kazuma, 2005; Todorovic, 2012; Sammut, Scerri and Xuereb, 2015; Radford, S.J. , McGing, J. , Czuber-Dochan, W. and Moran, 2020). Successful lifestyle modification has a positive effect on patients' HRQoL in LTCs (Allison, Locker and Feine, 1997; van der Have *et al.*, 2015). Individuals with LTCs often have to adjust their aspirations, lifestyle, and employment arrangements due to chronic symptoms such as fatigue (Obieglo *et al.*, 2014; van Houtum, Rijken and Groenewegen, 2015). Previous studies have shown that people with LTCs experience tension between managing their symptoms whilst being able to do what they would like to with their lives (Townsend, Wyke and Hunt, 2006; Nio Ong, Jinks and Morden, 2011). 'Normalising behaviours' were described during the interview study in terms of the participants incorporating fatigue management techniques into their daily lives. Participants using poor methods of fatigue management, such as task avoidance and all or nothing behaviours, experience higher levels of fatigue and worse HRQoL than those who do not (Habibi *et al.*, 2017; M. Artom *et al.*, 2017).

Group education for fatigue management in MS has been shown to offer improvements in fatigue and HRQoL when compared to no intervention. Participant education included

elements from cognitive behavioural therapy, focus on energy effectiveness, self-management and self-efficacy theories (Blikman *et al.*, 2013; Thomas *et al.*, 2014).

Multiple studies in IBD report that disengagement from social activity due to high levels of fatigue negatively impacts HRQoL (Tanaka and Kazuma, 2005; Faust *et al.*, 2012; Sammut, Scerri and Xuereb, 2015; Woodward *et al.*, 2016). The interview study revealed that the most common adaptation in the day-to-day lives of participants was a reduction of social interaction. Patients worry that their fatigue restricts not only their own, but also their families social activities (Woodward *et al.*, 2016). However, close relationships with friends, social support groups, networks and counselling are evidenced to positively impact on ability to better manage IBD fatigue, improving HRQoL (Sainsbury and Heatley, 2005; Faust *et al.*, 2012). Echoing the reports from study participants, perceived lack of social support has been shown to be related to increased levels of IBD fatigue (Tanaka and Kazuma, 2005). Social support, the sharing of concerns and experiences with family, friends and HCPs helps to maintain high levels of HRQoL (Lesage *et al.*, 2011; Haapamäki *et al.*, 2018).

Throughout the interview study the participants reported they made extra efforts to maintain a level of 'good general health', such as sustaining good nutritional intake and keeping physically active, this was done in order to better overcome feelings of fatigue. This was a particular element of 'self-management' reported by participants.

In some LTCs, such as MS, there is patient focused information available relating to the importance of making time to prepare and eat a healthy diet when managing a LTC, even when fatigued, however there is scarce information in IBD (*Diet and Nutrition for Energy with COPD | Cleveland Clinic*, no date; *Healthy eating | MS Trust*, no date; Forbes *et al.*, 2017). Managing dietary intake offers the individual a sense of control when living with a LTC which often presents unpredictable symptoms (Czuber-Dochan *et al.*, 2020). In IBD concerns related to diet only add to the level of discomfort and stress, for many this affects their ability to socialise. Food preparation is a task reportedly most put off by study participants due to levels of IBD fatigue. People with IBD strive for control, but this doesn't mean that many

achieve that sense of control over their symptoms, failing to maintain a healthy diet or having the ability to even prepare their own meals may compound the sense of a lack of control.

Graded exercise has been suggested as way of managing fatigue in LTCs including IBD, RA and MS (Hulme *et al.*, 2018). There is no evidence of negative side effects of moderate physical activity in people with stable IBD in remission (Narula and Fedorak, 2008; Engels, Cross and Long, 2018). Study participants reported that they found physical activity to reduce their levels of fatigue. Exercise has been shown to reduce fatigue and improve HRQoL in MS (Andreasen, Stenager and Dalgas, 2011; Khan, Amatya and Galea, 2014) RA (Cramp *et al.*, 2013) and chronic fatigue syndrome (Castell, Kazantzis and Moss-Morris, 2011; Larun *et al.*, 2017). Although not yet described in IBD, this has been discussed in various other LTCs with a focus on the health benefits of physical activity (Warburton, Nicol and Bredin, 2006). Most exercise interventions described utilise aerobic exercise, some use a combination of both aerobic and resistance exercise (Andreasen, Stenager and Dalgas, 2011; Castell, Kazantzis and Moss-Morris, 2011; Cramp *et al.*, 2013; Khan, Amatya and Galea, 2014; Larun *et al.*, 2017; Hulme *et al.*, 2018). There is little data regarding the impact of exercise on HRQoL in IBD, that which does exist is either of poor quality or is contradictory.

Conclusions

This is the first study to explicitly examine the experience of IBD related fatigue and its impact on HRQoL. Insights have been gathered into participants experiences of IBD fatigue and its effect on daily life.

The factors of HRQoL most impacted on by IBD fatigue were alterations made to daily life, through incorporation of management techniques into daily routine and the negative impact on social activities and relationships.

The recommendation for future research is to explore the role that patient self-management of symptoms have in improving levels of IBD fatigue and HRQoL in this cohort.

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Limitations:

Although adequate for an effective TA, the sample size of 14 was smaller than the planned 20. However, data saturation was met and has been shown to be achievable in TA with a sample size of 12 (Guest, Bunce and Johnson, 2006). Participants were self-selected, with many coming from the same established research patient group. It is possible that self-selected participants were inherently more open to talking about their experiences and are less representative of the wider IBD population. Further to this, it is also possible that those patients who are most symptomatic are the ones most willing to discuss symptoms and impact, also making this sample less representative of the wider IBD population. The data were coded, and themes identified by one person, the lead author, and the analysis then discussed with academic supervisors. This process allowed for consistency in the method but failed to provide multiple perspectives from a variety of people with differing expertise. For future research using this method, the coding of data should involve several individuals (Nowell *et al.*, 2017).

The lead author was aware of her previous professional experience of working with patients with IBD, recognising the importance of acknowledging, through reflexivity, the way these previous experiences may impact upon the approach and interpretation of information gathered during the course of the study. Although presented as a linear procedure, the research analysis was an iterative and reflexive process. The data collection and analysis stages in this study were undertaken concurrently, actively revisiting the previous stages of the process before undertaking further analysis to ensure that the developing themes were

grounded in the original data. In the process of reflexivity, the student was constantly adjusting behaviour, such as the type of questioning utilised, to benefit the research process (O'CONNOR, 2011). Recording thoughts after interviews and reflecting on these at the time of data analysis as a way of controlling for bias and consequently to improve the study rigour (Finlay, 2006; Creswell *et al.*, 2007). The position of the lead author throughout the research process presented an interesting point surrounding possible role conflict; novice researcher versus experienced Registered Nurse (RN). For this reason the lead author was explicit in detailing that participation was voluntary, had no implication on routine clinical care, participants were not under the clinical care of the student at the time of their participation and that withdrawal at any time was possible.

Ethical approval

The study was conducted in accordance with ethical principles that have their origin in the declaration of Helsinki, the principles of good clinical practice (GCP) and the framework for Health and Social Care (NHS Health Research Authority, no date; World Medical Association, no date).

Study Title (Main study)	Non-invasive approaches to identify the cause of fatigue in inflammatory bowel disease patients.
REC reference	***/**/**
Protocol number	*****
IRAS project ID	*****

Table 1: inclusion and exclusion criteria.

Inclusion criteria	Exclusion Criteria
<ul style="list-style-type: none">• Aged 16-75 years of age• BMI <30kg/m²• Diagnosed with CD <i>in remission, as displayed by:</i> <ul style="list-style-type: none">• HBI score <4 ³⁶• CRP <5 mg/L• Faecal calprotectin <50 ug/g ^{37,38} <i>Fatigued as defined by:</i> <ul style="list-style-type: none">• MFI-20 score >14 in any domain ³⁹	<ul style="list-style-type: none">• HADS >8• Haematological or biochemical abnormalities (E.g. Iron Anaemia)• Renal failure• Hypokalaemia• Pregnancy of childbearing in the last 6 months• Vitamin B complex deficiencies• Active or previous prescriptions of corticosteroids in the last 12 weeks• Overt muscle wasting (defined as 2 standard deviations outside the age-related norm as measured by DEXA)• Fatigue starting after the onset of Thiopurine therapy• Present arthritis or arthralgia• Surgical intervention in the last 12 weeks

Table 2: Sample characteristics

Sample characteristics	sd	
Age in years, mean (<i>sd</i>)	37.3	13.5
Female gender (%)	64	
Disease status		
Mean HBI score (<i>sd</i>)	2	1.5
Average disease duration (mean time since diagnosis of IBD in years)	9.2	7.4
Fatigue status		
Mean length of time fatigue has been present in years (<i>sd</i>)	10.9	4.6
Reported constant fatigue symptoms (%)	79%	
Reported intermittent fatigue symptoms (%)	21%	
Mean MFI-20 score (<i>sd</i>)	12.5	2.6
Mean IBD fatigue scale score (<i>sd</i>)		
Section 1	9	5.4
Section 2	47	15
Medications		
Immunosuppressants (%)	36	
Biologicals (anti-TNF) (%)	21	
Aminosalysate (Penstasa). (%)	7	
Antidepressants (%)	14	
Employment status		
full time Working/Student (%)	86	
Part time (%)	14	
unemployment (%)	0	
level of education		
A level or equivalent (%)	50	
Degree level (%)	21.5	
Postgraduate level (%)	21.5	
Doctoral level (%)	7	
Surgical intervention		
Ileostomy (%)	7	
Ileal resection (%)	29	
Hemicolectomy (%)	7	
Relationship status		
Married (%)	36	
Relationship/Co-habiting (%)	28	
Single (%)	36	
Smoking		
Never (%)	79	
Past (%)	14	
Current (%)	7	

Key: (%)=percentage of total sample (N=14); (**sd**)= standard deviation; **HBI**= Harvey Bradshaw Index Score; **MFI-20**= Multiple Fatigue Inventory- 20 questionnaire;

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