Perceptions of sleep in Inflammatory Bowel Disease and the acceptability of sleep interventions in routine care: A qualitative study

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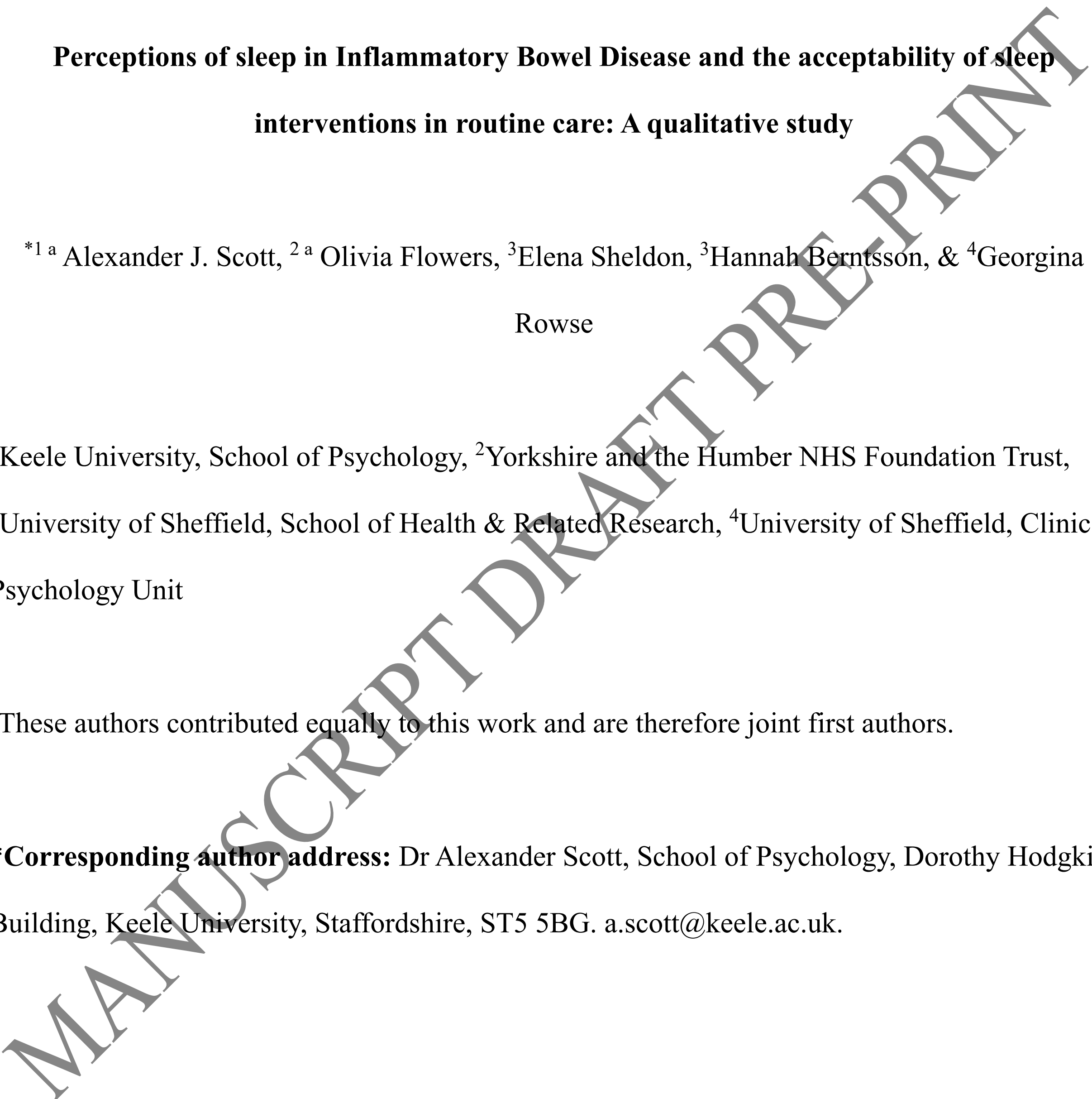

Abstract

There have been increased calls to manage poor sleep in Inflammatory Bowel Disease (IBD) care. However, it's unclear how people with IBD perceive their sleep to fit within their experience of IBD and whether interventions to improve sleep are acceptable. This qualitative study found that people with IBD perceive their sleep to be an integral part of living with IBD, would like more sleep support than is currently available, and find interventions for sleep broadly acceptable. It is important for future research to tailor sleep interventions towards those with IBD and explore the barriers to sleep support in routine care.

Keywords: Inflammatory Bowel Disease; IBD; Sleep; Qualitative

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30 **Perceptions of sleep in Inflammatory Bowel Disease and the acceptability of sleep**
31 **interventions in routine care: A qualitative study**

32 Inflammatory Bowel Disease (IBD) is an umbrella term for a collection of chronic and
33 incurable conditions characterized by relapsing and remitting inflammation of the
34 gastrointestinal tract (Ye et al., 2015). IBD is a global disease, with rates exceeding 0.3% of the
35 populations of many countries including North America, Oceania, and most countries in Europe,
36 with rising incidence across newly industrialized countries in Africa, Asia, and South America
37 (Ng et al., 2017). There is no 'cure' for IBD, so often the goal of treatment is to achieve and
38 maintain control of the disease symptoms, and to improve the quality of life of those living with
39 IBD (Bodger et al., 2014). However, meta-analysis of 29 studies conducted by van der Have et
40 al. (2014) concluded that disease symptom activity contributed to only 37% of the variance in
41 Health Related Quality of Life (HRQoL), suggesting that there remains a need to elucidate
42 additional, possibly modifiable determinants of quality of life in IBD above and beyond IBD
43 symptoms alone. More recently problems sleeping have been suggested as a possible behavioural
44 factor that could adversely affect IBD related outcomes and might represent a plausible treatment
45 target in IBD that warrants further exploration (Salwen-Deremer et al., 2020; Scott et al., 2020b).

46 **Sleep as a treatment target in IBD**

47 People living with IBD often report poor sleep quality. For example, Sochal et al. (2020)
48 reported that those with IBD reported significantly prolonged sleep onset latency, reduced sleep
49 efficiency, and poorer global sleep quality relative to healthy controls. Most extant literature has
50 tended to focus on the concept of 'sleep quality (i.e., a global measure indicating good or poor
51 sleep). However, more recent research has started to further delineate the role of poor sleep in
52 IBD by specifying types of sleep disturbance that might characterize the poor global sleep

quality seen in IBD. For example, Scott et al. (2020a) reported that when compared to healthy controls, those living with IBD report significantly more severe symptoms of sleep apnoea, insomnia, narcolepsy, nightmares, and restless-leg syndrome (see also, Becker et al., 2018; Hon, 2010). Consequently, we know that people living with IBD report poor global sleep quality, and that there might be some specific types of sleep disturbances that might explain this poor sleep quality in more granular detail.

The issue of poor sleep in IBD gathers more urgency when we consider longitudinal evidence that poor sleep might be a risk factor for poorer IBD related outcomes over time. For example, Uemura et al. (2016) reported a three-fold increase in IBD symptom flare-ups at a one year follow-up in those reporting poor global sleep quality at baseline. Furthermore, Scott et al. (2020b) reported that symptoms of insomnia and sleep apnoea were significant predictors of future IBD HRQoL, while Graff et al. (2013) found that poor sleep quality was predictive of changes in IBD related fatigue over time. Although experimental evidence is required, it's possible that improving sleep in those with IBD might confer benefits to a range of IBD outcomes (Salwen-Deremer et al., 2020; Scott et al., 2020b). For example, improving sleep in those with chronic health problems (although not in IBD) has been shown to also improve multiple areas that are particularly pertinent in IBD. These areas include mitigating the impact of chronic pain (Vitiello et al., 2013), as well as improving mental health (Scott et al., 2017; Wu et al., 2015), quality of life (Espie et al., 2008), and fatigue (Espie et al., 2008). Furthermore, laboratory induced sleep deprivation has been shown to increase inflammatory action, a key feature in the pathology of IBD (Mullington et al., 2010). Consequently, there are growing calls for the screening and subsequent treatment of sleep disturbances to be better integrated into routine IBD care (Green et al., 2017; Kinnucan et al., 2013; Salwen-Deremer et al., 2020; Scott

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76 et al., 2020b). However, despite these growing calls and possible benefits of improved sleep in
77 those with IBD, research exploring the role of sleep in peoples' experience of IBD and the
78 acceptability of improving sleep in IBD as a viable clinical treatment target is scarce (Salwen-
79 Deremer et al., 2020).

80 **The importance of mental health in the sleep-IBD relationship**

81 There is very little doubt that the physical symptoms of IBD can play an integral role in
82 the experience of poor sleep and represent a key factor that could explain the high prevalence of
83 problems sleeping in IBD (Hao et al., 2020). However, it's important to note that poor sleep can
84 be present in IBD even in the absence of active disease (Gîlc-Blanariu et al., 2020; Kinnucan et
85 al., 2013), and is not always associated with IBD disease symptom activity/severity (Marinelli et
86 al., 2020; Scott et al., 2020a). Consequently, IBD disease processes alone are likely not the only
87 driver of poor sleep. Although a comprehensive study of the determinants of poor sleep in IBD is
88 needed, one factor that might be particularly important is mental health (Marinelli et al., 2020;
89 Sochal et al., 2020). Indeed, poor sleep and poor mental health go hand-in-hand, with many mental
90 health difficulties being associated with problems sleeping (Scott et al., 2017). Furthermore, the
91 relationship between sleep and mental health (particularly anxiety and depression) appears to be
92 bidirectional in nature, with each being able to impact the other in a cyclical manner (Alvaro et al.,
93 2013). Given that there is a high prevalence of mental health difficulties (particularly anxiety and
94 depression) within people living with IBD (Mikocka-Walus et al., 2020), it is important that any
95 study of the sleep-IBD relationship considers the role of mental health as it is likely an important
96 determinant of poor sleep in IBD.

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97 **The present research**

98 The present qualitative research aims to explore three key questions that we hope will
99 facilitate more focus on sleep in IBD care. Firstly, to what extent do people with IBD perceive
100 their sleep to be associated with their IBD? Although there have been quantitative studies of the
101 association between sleep and IBD outcomes, to our knowledge no study has qualitatively
102 addressed how sleep fits with the experience of IBD. Secondly, what are the experiences of
103 people with IBD regarding the support they receive for sleep as part of routine care? Finally, to
104 what extent do people with IBD feel improving sleep as a route to improving IBD related
105 outcomes is acceptable? Although the evidence base suggests that improving sleep can lead to
106 benefits in important IBD related areas, it is not known if people living with IBD would perceive
107 such an intervention to be an acceptable method of improving their IBD. We hope that the
108 present research will not only aid our understanding of the role of sleep in IBD but will also
109 highlight current treatment provision for sleep in IBD, as well as providing a starting point for
110 the development of future interventions targeting sleep as a route to improving IBD related
111 outcomes.

112 **Materials and methods**

113 **Participants**

114 For full demographic characteristics, see Table 1. Participants were recruited through a
115 national IBD charity website and mailing list (Crohn's & Colitis UK) and via online IBD support
116 groups. Participants were eligible for inclusion if they had a diagnosis of IBD and were 16 years
117 old or over. In total, $N = 214$ participants consented to take part in the present research.

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Procedure and ethical considerations

This research was ethically approved by The School of Health and Related Research (ScHARR) Ethics Committee, at The University of Sheffield, UK. Participants were invited via email to complete an online qualitative survey relating to their sleep, mental health, and IBD. All data was collected anonymously online, using the survey hosting platform Qualtrics (Qualtrics, 2020).

Outcome measures

Demographics

Several demographic questions were asked to capture information relating to the participants age and sex, as well as IBD related demographics such as the type of inflammatory bowel disease, current stoma use, and the use of immunosuppressant medication. Participants were also asked whether they are currently receiving any medication or psychological therapies for problems sleeping, and/or mental health difficulties.

Qualitative Outcomes

Following consultation of the related literature an initial pool of items was shortlisted via group consensus of the authors to form a novel, 12-item qualitative survey (see Supplementary Materials 1). The survey was designed to elicit thoughts and feelings around two key domains; (i) four items exploring the role of sleep in IBD related outcomes and how mental health might fit in this relationship; and (ii) eight items exploring experiences with healthcare professionals regarding the management of sleep in routine IBD care and the acceptability of interventions aimed at improving sleep as a route to improving IBD outcomes. Survey items one to nine comprised an initial closed question (i.e., yes or no) designed to record frequencies of endorsement in one area of interest (e.g., "*do you feel that your mental health and your sleep*

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141 *quality are linked*?"), followed by an open-ended item which aimed to elicit further qualitative
142 responses around the previous item subject (e.g., *could you please explain why you feel that*
143 *way*?"). Items ten to twelve comprised only an open-ended question.

144 **Approach to Analysis**

145 Firstly, we report the frequency of responses to each closed item measured by the
146 qualitative survey. Secondly, participant responses to each item on the qualitative survey were
147 first entered into Nvivo v12 for thematic analysis. Analysis was conducted by three members of
148 the research team who analysed the data in line with Braun and Clarke's 6-stage inductive
149 thematic analysis (Braun and Clarke, 2006) which includes; (i) data familiarisation; (ii)
150 development of codes; (iii) searching for themes; (iv) reviewing themes; (v) defining and naming
151 themes; and, finally (vi) producing a report. Quotes from the participants that best represented
152 the views of the majority were used to illustrate each theme identified.

153 **Data sharing statement**

154 A de-identified data set that formed the basis of the analysis reported in the present
155 research will be uploaded in Excel format to the journal's FigShare repository upon publication.
156 The uploaded Excel file also includes a key to interpret all data in the main dataset (e.g., variable
157 types, names, and formats).

158 **Results**

159 Table 2 shows the response frequencies for each closed question. In summary, most
160 participants in the present research felt their sleep, mental health, and IBD symptoms are closely
161 linked, and would find improving sleep an acceptable way to improve their experience of IBD.
162 Despite this, although 80% of participants stated that they want their healthcare teams to address
163 their sleep, only 21% reported that healthcare professionals asked about sleep as part of their

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164 care. The analysis that follows describes the qualitative analysis of $N = 214$ participant responses
165 aiming to explore participant perceptions of two main areas; (i) the perceived relationship
166 between sleep, mental health, and IBD; and (ii) experiences around the management of sleep
167 during routine IBD care, and the acceptability of sleep interventions for IBD related outcomes.
168 For an overview of emergent themes, see Table 3 and Figure 1.

169 **Perceptions of the relationship between sleep, mental health, and IBD**

170 **Sleep, mental health, and IBD act together in a 'vicious circle'**

171 The majority of participants reported that their sleep, mental health, and IBD symptoms
172 are all inextricably linked in some way, with Participant 29 reflecting this point stating that, "*It's*
173 *the mind affecting the stomach and the stomach affecting the mind*". Participant 35 summarised
174 this well, "*I think they all effect each other. If I am stressed, my symptoms are worse, making me*
175 *feel low, and unable to sleep. If my symptoms are bad, I stress about it and can't sleep*".
176 Furthermore, many felt that if one of these three variables was negatively affected, then it would
177 have adverse consequences for the remaining variables. For example, Participant 7 commented
178 that sleep, mental health, and IBD are "*all linked and when one goes out of kilter, the others seem*
179 *to follow*". Conversely, many believed that improving one (or all) of these variables would lead
180 to improvements in the others. This point was reflected well by Participant 84, "*All three things*
181 *have such a big impact on your life as separate things, so a muddle of them all together is*
182 *hellish, one relieved makes a big difference*". Essentially, participants described the relationship
183 between sleep, mental health, and IBD symptoms as a 'vicious circle', and that improving one
184 element of this circle can improve the others. For example, "*the more I suffer with one of these*
185 *issues the more I suffer with the others. It's a vicious cycle that is hard to stop. But as one*
186 *improves it drags the others back to a more normal place*" (Participant 87).

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187 **The directionality of effect is perceived differently by different people**

188 Although the majority of participants felt that their sleep, mental health, and their IBD
189 symptoms were all interlinked, and bi-directional in nature, it was interesting to note that
190 different participants weighted either sleep, mental health, or IBD symptoms as more or less
191 influential as a causal aggravating factor that affects the other variables. In other words,
192 participants reported contrasting opinions on which variable was perceived to be at the start of a
193 causal chain of events.

194 ***IBD symptoms as a causal factor***

195 The most common perception was that the symptoms of IBD are the most influential
196 causal factor behind both the experience of mental health difficulties, and problems sleeping.
197 Some participants reported that IBD symptoms lead to worse mental health, which in turn leads
198 to problems sleeping. Participant 23 summarised this point well, stating, "*I think IBD has made*
199 *me more depressed, worthless feeing etc., and then when I have accidents with IBD it makes me*
200 *feel even worse. When I'm having a bad time with IBD I feel like I'm letting everyone down and*
201 *can't control my life. Both of these make it hard to sleep*". Participant 7 echoed this sentiment, "*It*
202 *feels like an endless cycle, fatigue causes more stress, stress makes it more difficult to sleep and*
203 *relax, which causes more fatigue and so on*". Many participants suggested that if their IBD
204 symptoms were less severe, that their mental health would be better, and consequently they
205 would have less difficulty sleeping. This point is summarised well by Participant 12, "*if the*
206 *symptoms were to get better I could relax more, so my sleep would be better*". Other participants
207 suggested that their IBD symptoms lead to disturbed sleep, which in turn impacted on mental
208 health. For example, Participant 64 stated that, "*IBD symptoms often disturb sleep (pain, having*
209 *to use the bathroom in the night) often making one more anxious and depressed, so it becomes a*

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210 *vicious circle*". Similarly, Participant 15 stated that, "*less [IBD] symptoms means I get much*
211 *better sleep, which definitely improves my mental health*".

212 ***Problems sleeping as a causal factor.***

213 Many participants perceived problems sleeping as the factor that can aggravate both
214 mental health difficulties and IBD symptoms, a point reflected by Participant 16, "*I always feel*
215 *more pessimistic about my ability to function when sleep deprived. Lack of sleep also often*
216 *aggravates my bowel symptoms making my mental health worse*". Additionally, Participant 73
217 commented that, "*When you don't sleep overly well, you start to feel drained, run down and*
218 *depressed. Your pain threshold decreases so you get stressed. Being stressed caused the IBD to*
219 *react and flare up*". Similarly, Participant 54 commented that "*a lack of sleep often causes*
220 *increased anxiety and I have found that this can worsen my IBD symptoms*". Conversely, some
221 participants suggested that when they are able to sleep well, their IBD symptoms were less
222 impactful, "*Since I have not been working and able to sleep more often when I can, when I need*
223 *to, my symptoms eased considerably and I was eventually able to reach near remission. When I*
224 *don't get sufficient rest my bowels can play up*" (Participant 77). Similarly, sleeping well was
225 perceived to lead better mental health, as summarized by Participant 39, "*If I get the right*
226 *amount of sleep I am more relaxed and energized. The more relaxed I am, the better I feel. My*
227 *symptoms calm down when not stressed*", and Participant 87 stated, "*If I sleep better, my mental*
228 *wellbeing feels better*".

229 ***Mental health difficulties as a causal factor***

230 Other participants weighted their mental health more heavily as a causal factor that can
231 exacerbate problems sleeping and IBD symptoms. The most common view was that experiences
232 of depression, anxiety, and stress can lead to poorer sleep, and worse IBD symptoms. For

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233 example, Participant 4 stated that, “*Mental health problems affect how tired I am and how well I*
234 *sleep, this can then affect my Crohn’s as it increases the fatigue and occasionally due to stress*
235 *can lead to worsening of symptoms*”. Likewise, Participant 47 commented, “*When I feel*
236 *depressed or anxious, it tends to break my sleep up and make my IBD kick in*”.

237 **Poor sleep can lead to difficulties ‘thinking clearly’**

238 Many participants reported that poor sleep quality had a negative impact on their ability
239 to think clearly, generally suggesting that poor sleep impacts adversely on cognition, “*I don't*
240 *sleep enough therefore never have a clear mind. I'm always tired and can never think straight*”
241 (Participant 58). For example, Participant 37 said, “*I know that If I don't get enough sleep I don't*
242 *think as logically as I otherwise would*”, while Participant 4 stated, “*I also realize that if I had*
243 *better sleep habits then I would probably have a better memory and be generally less tired. The*
244 *knock on effect would be me getting more done and so feeling more productive*”. Other
245 participants believed that poor sleep made it difficult to process and respond to emotion, a point
246 summarised well by Participant 72, “*When I am well rested, I am more able to be myself and*
247 *deal with things that come up in a proactive way. When I am not well rested, I have difficulties*
248 *with processing my emotions or responding appropriately*”. Finally, some participants felt that
249 impaired cognition lead to problems with mental health and/or coping. Participant 89
250 summarized this in relation to depression, “*When I am depressed I know it affects my sleep*
251 *patterns, likewise when my sleep is disturbed (by anything) I know I start to get more depressed*
252 *as I am too tired to rationalize ideas that cause depression*”.

253 **Poor sleep can make it harder to cope with mental health and IBD**

254 Another key theme arising from the present research was that, in the presence of poor
255 sleep, coping with both mental health and IBD symptoms, as well as the impact both have on

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256 daily life, is much harder. For example, Participant 80 summarised the impact of poor sleep on
257 coping with IBD symptoms well, "*If I am tired then I cannot deal with my IBD symptoms as well*
258 *as I should be. I do not have as much tolerance for the bathroom visits and the stopping what I*
259 *am doing to go to the bathroom*". Likewise, Participant 94 said that, "*Lack of sleep also affects*
260 *my perception of my Crohn's meaning that I don't cope as well, physically or mentally*", while
261 Participant 38 comment that, "*Being tired and a lack of sleep saps my ability to 'hack' the IBD*
262 *symptoms or form a coherent plan regarding them*". Conversely, participants generally reported
263 that when they sleep well, dealing with life as someone with IBD is easier. This notion was
264 reflected by Participant 94, "*If I had better quality sleep, my ability to cope day-to-day with my*
265 *Crohn's, especially the pain, would be vastly improved*". Similarly, Participant 96 stated that
266 "*More sleep does seem to alleviate my joint pain, and also reduces my worry slightly. I seem to*
267 *take my IBD in my stride more often if I am fully relaxed*". Many participants felt that poor sleep
268 generally amplified the impact of poor mental health and IBD. For example, Participants 78
269 stated "*My feelings of depression are definitely heightened on days where I have had fewer hours*
270 *of sleep than my body needs*", and Participant 77 commented, "*I have significant mental health*
271 *issues, and they definitely get worse when I'm very tired. I get more depressed and find it harder*
272 *to look after myself well, which leaves me more physically ill too*".

273 **Management of sleep during routine IBD care: current provision and acceptability**

274 **"They don't ask unless I bring it up"**

275 The overwhelming majority of participants reported that health professionals have never
276 addressed sleep with them when discussing their IBD. Participant 87 stated, "*I have never been*
277 *asked about my sleep or indeed my mental state by any IBD professional during the 18 years I*
278 *have been diagnosed*". Many described having raised the topic of poor sleep themselves, where

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279 health care professionals had not. Participant 76 commented "*it's never been mentioned until I*
280 *mentioned it and I got told that it [poor sleep] can be a side effect and that was pretty much it*".
281 Reports of little to no help being offered and feelings of dissatisfaction were echoed by others.
282 For instance, participant 94 stated that "*it's always been treated as an irrelevance, not as*
283 *something that is a contributory factor in my Crohn's. I've always felt they think it's something*
284 *that I just have to learn to live with*", whilst participant 31 commented "*when fatigue is*
285 *mentioned it doesn't seem like they have a lot of suggestions to help*".

286 **Sleep addressed only in relation to physical IBD symptoms**

287 Some participants felt health professionals only raised the topic of sleep in relation to
288 physical IBD symptoms. Questions about sleep were considered a method of determining how
289 severe the condition was by participant 134, "*my gastro consultant uses how many times sleep is*
290 *disturbed by the condition to gauge how good/bad the symptoms are*". Others commented that
291 quality of sleep and general sleeping patterns were not addressed in discussions, which mainly
292 focused on physical symptoms. Participant 40 emphasized this, commenting that "*the only time I*
293 *am asked about my sleep is in relation to my symptoms, [for example] if needing the toilet is*
294 *waking me up at night. My actual ability to sleep, or my quality of sleep is never addressed*",
295 whilst participant 84 stated, "*I've been asked how often I get up to go to the toilet during the*
296 *night. But never about my general sleeping patterns*".

297 **Mixed experiences of mental health discussions with health professionals**

298 Whilst over half the participants reported that health professionals had never discussed
299 their mental health with them in relation to their IBD, there were some mixed experiences
300 regarding this. A number of participants felt the impact of IBD on their mental health was never
301 addressed, participant 208 stated, "*none of my healthcare providers have asked me how I've been*

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302 *affected emotionally or mentally by my diagnosis*". Others expressed a feeling that health
303 professionals were concerned only with physical IBD symptoms, participant 183 commented
304 "*they're only concerned with bowel symptoms*". Conversely, some participants did report being
305 asked about their mental health. For example, participant 85 stated, "*my GI doctor checks in on*
306 *my mental health and how I am managing*". Others commented they were often asked how they
307 were coping, for example Participant 109 reported, "*I am always asked how I'm feeling/coping*".
308 The help offered in response to discussions about mental health also varied greatly. Whilst some
309 described being offered therapy, such as participant 131, "*I was prescribed therapy to deal with*
310 *the changes*", others referred to their use of medications to help with mental health difficulties, as
311 depicted by participant 32, "*I've been put on many different drugs for depression*". Some
312 participants expressed dissatisfaction with the response to mental health problems. Participant 89
313 said, "*they just brush it off as if it's normal*" when mental health is raised, whilst participant 77
314 commented, "*I don't believe they want to address the issues head on*".

315 **IBD care requires a holistic approach to "treat all aspects"**

316 Participants identified a need for an integrated treatment approach whereby healthcare
317 services address sleep and mental health as part of routine IBD care. Participant 118 highlighted
318 that, "*holistic approaches to IBD treatment would be a much more successful approach. Many*
319 *sufferers of IBD suffer silently with mental health issues related to their physical condition. It*
320 *would be beneficial for hospitals and GPs to have linked services with counselling or support*
321 *groups available*". The notion that this level of support is unavailable to most patients, and
322 negatively impacts on their standard of care, was emphasised by Participant 178 stating that, *"If*
323 *my doctors were aware of everything, and knew the real implications of them, it might work to*
324 *help me to get the correct help at the correct time, not several months down the line if not at*

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325 *all… with doctors not working together, everything is bitty and I don't seem to get any better".*
326 The benefits to a holistic approach primarily concerns mental health; for example, Participant 38
327 commented that, *"I think IBD is directly related to mental health and there isn't any help to go*
328 *with it. I feel like the option to speak to someone when you first get diagnosed should be there, it*
329 *would've made everything a whole lot easier. I still wish I had counselling now and it's been 2*
330 *years".* Patients' responses therefore suggest that IBD symptoms, mental health, and other
331 aspects of the disease should be assessed collectively across a variety of services and not treated
332 in isolation from one another.

333 **Sleep intervention as a key route to 'keeping IBD at bay'**

334 Most participants voiced the opinion that a sleep intervention would be an acceptable and
335 beneficial way of alleviating IBD symptoms, particularly with experiences of stress, exhaustion
336 and fatigue. For example, Participant 143 commented that "*better sleep will mean better IBD*
337 *symptoms with hopefully less fatigue in the daytime*". This point was reinforced by Participant 33
338 stating that, "*I think more sleep would hopefully lessen the fatigue symptoms and help with the*
339 *effects of my IBD by reducing anxiety and stress*", and Participant 93 commenting that, "*I might*
340 *not be exhausted all the time which in turn could improve the quality of life*". Longer-term
341 benefits were also identified both in terms of reducing the risk of relapse, coping with IBD in
342 day-to-day life and improving general quality of life. Participant 73 for instance suggested that a
343 sleep intervention would benefit by, *"keeping IBD at bay and avoiding a flare up"* in the future.
344 The benefits of a sleep intervention for an IBD patient are aptly summarised by Participant 38,
345 "*the ability to cope, physically and mentally, with a chronic illness … just by acknowledging it as*
346 *a factor, it can make patients feel that they aren't the only one dealing with this as part of their*
347 *illness which can make it easier to cope. The medical profession needs to be aware how large a*

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348 *part of a patient's illness sleeplessness can be and the impact it has on both physical and mental*
349 *health. It needs to be recognised as being just another factor in the management of a chronic*
350 *illness, with parity with other symptoms"*.

351 **Sleep interventions are acceptable, but one size does not fit all**

352 Although the idea of a sleep intervention was generally well accepted by participants,
353 preferences for the content and mode of delivery widely varied. For example, Participant 153
354 suggested that, *"apps would be great and less time consuming, also* [can be] *done in your own*
355 *time and when/if needed"*. This contrasts to Participant 80 who preferred, *"face-to-face as I think*
356 *opening up a dialogue is more useful to help someone begin to get help and move on to helping*
357 *themselves once they have the tools and mental strength and knowledge to do so".* Other
358 participants suggested self-help booklets as potentially helpful, as *"having something to read*
359 *certainly helps make things more concrete and helps to remember them"* (Participant 47)*,*
360 whereas other participants rejected this idea because, *"if you are already depressed then the*
361 *energy and enthusiasm for filling in sheets isn't there, especially as the hospital won't take any*
362 *notice of them"* (Participant 91). There was also a general willingness of participants to try a
363 combination of approaches to improve sleep quality, including apps to improve sleep,
364 pharmacological treatments, self-help sleep programmes, and face-to-face interventions. For
365 example, Participant 19 noted that, *"I'd like there to be a few ways to try and help to see what*
366 *works best for each person"* and Participant 206 commented that "*a mixture of face to face,*
367 *through apps or other technology and, if necessary, more medication"*. Taken together, these
368 findings suggest the need for individual care plans tailored to the personal preferences of patients
369 and identified needs.

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370 **Discussion**

371 The present research aimed to qualitatively explore perceptions of the role of sleep and
372 mental health in the experience of IBD, to understand the current level of support for problems
373 sleeping in routine care, as well as the acceptability of improving sleep as a route to improving
374 IBD related outcomes. We found that people living with IBD perceived their sleep, mental
375 health, and IBD to interact in a 'vicious circle', with each being able to influence the other. We
376 also found that the poor sleep experienced in IBD can lead to perceived difficulties 'thinking
377 clearly', and ultimately makes life with IBD harder to cope with. Furthermore, we found that the
378 majority of participants reported wanting support for their sleep, but that very few participants
379 actually received support. Importantly, most felt the idea of improving sleep as a tool to 'keep
380 IBD at bay' was acceptable as part of a greater holistic care approach. Indeed, a major theme
381 arising from the present research was that people living with IBD feel that routine care requires
382 more emphasis on a holistic approach that is able to treat all aspect of living with IBD, sleep and
383 mental health included. However, participants expressed diverging opinions on the content of the
384 intervention as well as how an intervention might be delivered, and in what setting.
385 Consequently, a 'one size fits all' approach to intervention is unlikely to be effective, suggesting
386 the need for more research into adapting and tailoring interventions to support sleep in IBD.

387 **Sleep perceived as more than just an epiphenomenon of IBD**

388 One of the key messages from the present research is that the majority of participants in
389 the present study felt that their sleep was able to influence their mental health and IBD symptoms
390 (and vice versa), suggesting that participants perceived sleep to have a more influential role,
391 rather than simply an epiphenomenon of IBD symptoms themselves. The idea that sleep is not
392 just a product of IBD symptoms, and can have a more influential role in the experience of IBD

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393 related outcomes is one that is growing empirical support (Scott et al., 2020b; Uemura et al.,
394 2016). This is an important finding in that the present research also highlighted that participants
395 also felt that when healthcare professionals do address sleep, it is generally only ever in relation
396 to the physical IBD symptoms themselves. Of course, it is important to stress that we do not
397 contest the idea that improved IBD symptoms would lead to improved sleep quality, it almost
398 certainly would in many cases. Indeed, the present study found that participants felt their IBD
399 symptoms do lead to poor sleep and poor mental health. However, we would argue that the
400 reverse could *also* be true, in that improving sleep could also lead to improvements in other IBD
401 related outcomes. Sleep is increasingly being conceptualized as a 'transdiagnostic' process in that
402 is able to cut across many different health experiences and diagnoses as a 'core' process (Hale et
403 al., 2020). The present research demonstrates that people living with IBD support this notion.
404 However, the evidence for this type of relationship specifically in IBD is lacking, therefore
405 future research might profitably examine the relationship between sleep and IBD related
406 outcomes in more detail by studying the possible bidirectional links that we see in other areas.
407 **Understanding barriers to the implementation of sleep intervention in IBD care**
408 Despite 80% of the participants surveyed in the present research expressing a desire for
409 more support with their sleep, only 21% reported receiving support for sleep, a finding that was
410 reflected in the qualitative analysis. Given that present research found that people with IBD
411 perceive their sleep to be an important and influential part of their IBD, and that improving sleep
412 might have additional benefits to IBD related outcomes, future research might try to elucidate the
413 barriers to providing sleep support in routine IBD care. For example, it might be that IBD
414 clinicians do not have the time or remit to provide systematic support for sleep, do not know
415 about the associations between sleep and wider IBD related outcomes, or that they lack the

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416 required training in sleep disorder screening and treatment (Meaklim et al., 2020). Furthermore,
417 it is unclear where in the IBD care infrastructure sleep interventions might be best placed. This
418 mismatch is perhaps not surprising given the complexity of care in IBD, and that joined-up
419 multidisciplinary support with a view to proving holistic IBD care is difficult to achieve in
420 clinical services (Egberg et al., 2018). We recommend that future research explores possible
421 barriers to both the assessment and screening of sleep disturbances, and the implementation of
422 sleep interventions in routine care so that some of the complexities can be better understood.
423 Indeed, given our finding that the need for holistic care that supports all aspects of living with
424 IBD is important to patients, it's important that future research aims to also understand the
425 barriers to holistic care so that the need for more comprehensive support in IBD care can be
426 realised.

427 **Cognitive Behavioral Therapy for Insomnia (CBTi) as an intervention option in IBD**

428 The findings presented here suggest that people living with IBD think that improving
429 sleep as a route to improving IBD related outcomes acceptable, but that a generic 'one size fits
430 all' approach might not be effective. Most participants stated that although they want more
431 support with their sleep, very few receive such support. Although few studies have looked at the
432 specific types of sleep disturbances experienced in IBD, the evidence we do have suggests that
433 insomnia is particularly problematic (Scott et al., 2020a, 2020b). With this in mind, one
434 intervention that might be particularly well placed to improve sleep in people with IBD is
435 cognitive behavioural therapy for insomnia (CBTi, Salwen-Deremer et al., 2020). CBTi is the
436 recommended first line treatment for insomnia and has been shown to be effective at improving
437 sleep in both face to face (Trauer et al., 2015), and digitally delivered formats (Luik et al., 2019).
438 Importantly, improving sleep using CBTi might also improve other concomitant areas of IBD,

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439 including pain (Vitiello et al., 2009), and mental health difficulties (Christensen et al., 2016).
440 Furthermore, given that there is no cure for IBD, it is likely that the problems sleeping
441 experienced by those with IBD will also be a long-term issue. Short term pharmacological
442 approaches to improving sleep, not only increase polypharmacy in chronic disease (Buckley et
443 al., 2013), a possible risk factor for increased IBD symptom flares (Wang et al., 2019), but also
444 come with the risk of addiction, dependence, and developing tolerance leading to needing higher
445 doses to achieve good effect (Frase et al., 2018). CBTi on the other hand, has the potential to
446 equip people with IBD with tools and strategies to ameliorate poor sleep for the longer term
447 whilst empowering people to take control over an important aspect of their health (Green et al.,
448 2017).

449 To our knowledge, no study has tested the effect of interventions such as CBTi in people
450 with IBD on both sleep itself, and wider IBD outcomes. Given that CBTi has been shown to
451 improve sleep and wider health outcomes in those with other chronic health conditions (Espie et
452 al., 2008; Vitiello et al., 2013; Wu et al., 2015), future research might profitably test the effect of
453 CBTi in IBD. However, it is important to remember that 'off the shelf' CBTi is not geared
454 towards people with physical health problems. In fact, a common problem when implementing
455 behaviour change interventions in different populations is that there is often a mismatch between
456 the original target population (i.e., people with insomnia) and the new target population (i.e.,
457 people with IBD and problems sleeping) that presents a number of challenges. For example,
458 people living with IBD often experience physical health problems that can directly interfere with
459 sleep (e.g., abdominal pain and needing to use the bathroom throughout the night), an increased
460 prevalence of mental health difficulties that affect sleep (Mikocka-Walus et al., 2020), as well as
461 the adverse effects that some IBD treatments and management options have on sleep (e.g.,

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462 steroid medication, surgery). Moreover, IBD specific characteristics not only present challenges
463 for CBTi intervention content, but also for its delivery. For example, people living with IBD
464 experience substantial daily disease burden (Le Berre et al., 2020), and can experience
465 debilitating fatigue (Borren et al., 2019), both of which could impact the ability to engage with a
466 CBTi intervention itself (Hanlon et al., 2020). Consequently, CBTi content and the method of
467 delivery would likely need to be adapted and tailored towards those with IBD to account for
468 these specific challenges.

469 **Limitations of present research**

470 The present research builds on extant literature exploring the role of sleep in the
471 experience of IBD by reporting a qualitative analysis using a large sample of people living with
472 IBD. However, there are some limitations around the generalizability of the sample that should
473 be considered when interpreting the findings. Firstly, the present research recruited an online
474 volunteer sample of participants, therefore it is possible that there could be differences in the
475 characteristics (e.g., demographic and clinical) of those who volunteer for a study and those who
476 do not. Given that the relevance or salience of a given research topic is likely to influence
477 peoples decision to volunteer, it's possible that the present research recruited a sample of
478 participants with IBD who might report more severe sleep disturbances than those who do not
479 volunteer. Secondly, we relied on self-reported diagnoses of IBD rather than clinician confirmed
480 cases. However, given that we limited recruitment to IBD specific sources (e.g., IBD support
481 groups and a national IBD charity), and the fact that there is often a very high agreement
482 between self-reported diagnosis of IBD and clinician confirmation (Kelstrup et al., 2014), we
483 believe the effect on the present findings will be minimal. Nevertheless, future research might
484 consider using a sampling method that is able to provide more generalizable findings using a

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485 more representative sample of people living with IBD. However, we believe that any differences
486 would be in degree rather than kind.

487 **Conclusions**

488 The take home messages of the present research are that people living with IBD; (i)
489 perceive their sleep to be an important and influential part of their IBD; (ii) think that improving
490 sleep might improve their wider IBD symptoms and experiences; and (iii) that interventions to
491 support sleep in IBD are acceptable, but that ‘one size does not fit all’. Despite this, few
492 participants reported receiving support with their sleep, with most expressing a desire for a
493 holistic approach to IBD care that encompassed symptoms and wider outcomes such as sleep.
494 We think that a key next step in the field is to understand the adaptations that might be required
495 to existing interventions, like CBTi, that we know can be effective, before experimentally testing
496 such adapted interventions. Overall, participants expressed a desire to integrate sleep support
497 within their healthcare, suggesting that a valuable area for future research is to explore the
498 reasons why support for problems sleeping is rarely available within the routine management of
499 IBD so that we might circumvent barriers to the implementation of sleep assessment and
500 intervention in IBD care. Improving sleep is important in its own right and will likely improve
501 quality of life on its own. However, improving sleep has been shown to be effective in improving
502 other areas associated with IBD such as pain and mental health difficulties. Consequently, sleep
503 might be viable and important factor within the management IBD, and one that might ultimately
504 improve patient care.

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622 **Table 1**

623 *Demographic and Clinical Characteristics of Participants (N = 214)*

Variables	M	SD
Age	34.69	11.61
	N	**%**
Sex		
Male	44	21%
Female	170	79%
Diagnosis		
Crohn's Disease	132	63%
Ulcerative Colitis	78	37%
Current stoma use		
Yes	30	14%
No	180	86%
Using immunosuppressant medication		
Yes	133	63%
No	77	37%
Accessing psychological support for sleep?		
Yes	11	5%
No	199	95%
Using medication for sleep?		
Yes	43	21%
No	167	79%
Accessing psychological support for mental health?		
Yes	30	14%
No	180	86%
Using medication for mental health?		
Yes	68	32%
No	142	68%

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625 **Table 2**

626 *Frequency and Proportion of Reponses to Closed (Yes/No) Items on the Qualitative Survey*

Item	Yes, *N* (%)	No, *N* (%)
Do you feel that your mental health and your sleep quality are linked?	185 (86%)	29 (14%)
Do you feel that your mental health and your IBD symptoms are linked?	179 (86%)	29 (14%)
Do you feel that your sleep quality and your IBD symptoms are linked?	166 (80%)	41 (20)
Do you believe that changes in one of these factors – be that sleep, mental health or IBD symptoms – has an effect on any of the others?	200 (97%)	6 (3%)
In your experience, have health professionals (e.g. your doctors, GP, nurses, etc.) addressed, or asked about your sleep when they are discussing your IBD?	44 (21%)	161 (79%)
Would you want healthcare professionals to address your sleep with you when they are discussing your IBD?	163 (80%)	42 (20 %)
In your experience, have health professionals (e.g. your doctors, GP, nurses, etc.) addressed, or asked about your mental health when they are discussing your IBD?	78 (38%)	127 (62%)
Would you want them to address your mental health with you when they are discussing your IBD?	165 (81%)	39 (19%)
Would you find being offered an intervention to help improve your sleep an acceptable way of trying to improve your IBD symptoms?	126 (62%)	78 (38%)

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Table 3

An Overview of Major Themes and Illustrative Quotes from Participants

Domain	Theme	Sub-theme	Summary	Quote
Perceptions of the relationship between sleep, mental health, and IBD	Sleep, mental health, and IBD act together in a 'vicious circle'	-	Sleep, mental health, and IBD symptoms are all inextricably linked in some way, with each being able to impact the other.	"*the more I suffer with one of these issues the more I suffer with the others. It's a vicious cycle that is hard to stop. But as one improves it drags the others back to a more normal place*" (participant 87).
	The directionality of effect is perceived differently by different people	-	Participants reported that their sleep, mental health, and IBD symptoms are all interlinked. However, participants reported contrasting opinions on which variable was perceived to be at the start of a causal chain of events	-
		IBD symptoms as a causal factor	The most common perception was that the symptoms of IBD are the most influential causal factor behind both the experience of mental health	"*if the symptoms were to get better I could relax more, so my sleep would be better*" (participant 12).

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Domain	Theme	Sub-theme	Summary	Quote
			difficulties, and problems sleeping	
		Problems sleeping as a causal factor	Many participants perceived problems sleeping as the factor that can aggravate both mental health difficulties and IBD symptoms	"*a lack of sleep often causes increased anxiety and I have found that this can worsen my IBD symptoms*" (participant 54).
		Mental health difficulties as a causal factor	Other participants weighted their mental health more heavily as a causal factor that can exacerbate problems sleeping and IBD symptoms	"*Mental health problems affect how tired I am and how well I sleep, this can then affect my Crohn's as it increases the fatigue and occasionally due to stress can lead to worsening of symptoms*" (participant 4).
	Poor sleep can lead to difficulties 'thinking clearly'	-	Many participants reported that poor sleep quality had a negative impact on their ability to think clearly, generally suggesting that poor sleep impacts adversely on cognition	"*I also realize that if I had better sleep habits then I would probably have a better memory and be generally less tired. The knock on effect would be me getting more done and so feeling more productive*" (participant 4).
	Poor sleep can make it harder to	-	Another key theme arising from the present research was	"*If I had better quality sleep, my ability to cope day-to-day with my*

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Domain	Theme	Sub-theme	Summary	Quote
	cope with mental health and IBD		that, in the presence of poor sleep, coping with both mental health, IBD symptoms, and the impact both have on daily life is much harder	*Crohn's, especially the pain, would be vastly improved*" (participant 94).
Management of sleep during routine IBD care: current provision and acceptability	They don't ask unless I bring it up	-	Participants reported that health professionals have never addressed sleep with them when discussing their IBD	"*it's never been mentioned until I mentioned it and I got told that it can be a side effect and that was pretty much it*" (participant 76).
	Sleep addressed only in relation to physical IBD symptoms	-	Some participants felt health professionals only raised the topic of sleep in relation to physical IBD symptoms	"*the only time I am asked about my sleep is in relation to my symptoms, [for example] if needing the toilet is waking me up at night. My actual ability to sleep, or my quality of sleep is never addressed*" (participant 40).
	IBD care requires a holistic approach to "treat all aspects"		Participants identified a need for an integrated treatment approach whereby healthcare services address sleep and	*"If my doctors were aware of everything, and knew the real implications of them, it might work to help me to get the correct help at the correct time, not several months down*

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Domain	Theme	Sub-theme	Summary	Quote
			mental health as part of routine IBD care	*the line if not at all… with doctors not working together, everything is bitty and I don't seem to get any better"* (participant 178).
	Sleep intervention as a key route to 'keeping IBD at bay'		Most participants voiced the opinion that a sleep intervention would be an acceptable and beneficial way of alleviating IBD symptoms, particularly with experiences of stress, exhaustion and fatigue	"*The medical profession needs to be aware how large a part of a patient's illness sleeplessness can be and the impact it has on both physical and mental health. It needs to be recognised as being just another factor in the management of a chronic illness, with parity with other symptoms"* (participant 38).
	Sleep interventions are acceptable, but one size does not fit all		Although the idea of a sleep intervention was generally well accepted by participants, preferences for the content and mode of delivery widely varied	*"I'd like there to be a few ways to try and help to see what works best for each person"* (participant 19).

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Figure 1

Major Themes Arising from Qualitative Analysis

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