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13 **Abstract**

14 Inflammatory Bowel Disease (IBD) is commonly associated with poor global sleep  
15 quality, and has been posited as a modifiable determinant of IBD related outcomes, with  
16 recent calls to screen for, and subsequently treat problems sleeping as part of routine IBD  
17 care. However, there is little evidence on the specific *types* of problems sleeping (e.g., sleep  
18 apnea, insomnia etc.) that might characterize the poor sleep quality experienced by those with  
19 IBD. The present research aimed to investigate the severity of seven specific types of  
20 problems sleeping in those with IBD vs. a healthy control group. This cross-sectional  
21 comparison study recruited  $N = 409$  with IBD, and  $N = 377$  healthy controls (total sample  $N$   
22  $= 786$ ). The Sleep-50 questionnaire was used to assess the presence of seven types of  
23 problems sleeping. Multivariate Analysis of Covariance (MANCOVA) was used to compare  
24 the severity of sleep disturbances between the IBD and control groups. Those in the IBD  
25 group reported significantly more severe experiences of five of the seven domains of the  
26 Sleep-50, including increased; sleep apnea, insomnia, narcolepsy, restless legs, and  
27 nightmares. In conclusion, those with a diagnosis of IBD reported significantly more severe  
28 symptoms across a range of specific problems sleeping when compared to controls. More  
29 research is needed to; i) improve the identification and treatment of problems sleeping in  
30 routine care; ii) understand the mechanism(s) of action that links problems sleeping to IBD  
31 related outcomes; and iii) develop adapted interventions to improve sleep in those with IBD.

32 Word count: 246

33 *Keywords:* Sleep; Inflammatory Bowel Disease; IBD; Crohn's Disease; Ulcerative  
34 Colitis.

35

36           **A Comparative Study of the Nature and Magnitude of Problems Sleeping in**  
37           **Inflammatory Bowel Disease (IBD) Compared to Healthy Controls**

38           In recent years, there has been a proliferation of research aiming to better understand  
39 the role of sleep in a range of physical (Gallicchio & Kalesan, 2009; O'brien et al., 2010;  
40 Pavlova, Ference, Hancock, & Noel, 2017; Wong et al., 2013), and mental health difficulties  
41 (Baglioni et al., 2011; Scott, Rowse, & Webb, 2017; Taylor, Lichstein, Durrence, Reidel, &  
42 Bush, 2005). The association between problems sleeping and health is particularly apparent  
43 in those with Inflammatory Bowel Disease (IBD) - a chronic and incurable disease involving  
44 inflammation of the gastrointestinal tract – where poor sleep quality is commonly reported  
45 (Kinnucan, Rubin, & Ali, 2013; Swanson, Burgess, & Keshavarzian, 2011; Wilson et al.,  
46 2015). Indeed, problems sleeping in those with IBD have been posited as a modifiable risk  
47 factor for a number of IBD related outcomes including diagnosis incidence (Ananthkrishnan  
48 et al., 2014), disease symptom flares (Ananthkrishnan, Long, Martin, Sandler, &  
49 Kappelman, 2013; Uemura et al., 2016), poorer health related quality of life (Keefer,  
50 Stepanski, Ranjbaran, Benson, & Keshavarzian, 2006; Ranjbaran, Keefer, Stepanski, Farhadi,  
51 & Keshavarzian, 2007; Uemura et al., 2016), and fatigue (Graff et al., 2013). However,  
52 despite a growing body of literature further elucidating our understanding of the experience  
53 of sleep in those with IBD, there remains a number of opportunities that would facilitate calls  
54 to screen for, and subsequently treat problems sleeping in those with IBD (Almedimigh et al.,  
55 2018; Kinnucan et al., 2013).

56           **Opportunities for Advancement**

57           To date, the majority of research into the role of sleep disturbances in those with IBD  
58 has tended to rely on more global measures of sleep quality (e.g., the Pittsburgh Sleep Quality  
59 Index (PSQI); Buysse, Reynolds, Monk, Berman, & Kupfer, 1989), rather than measures able  
60 to detect *specific* types of problems sleeping. For example, the PSQI can tell us somebody

61 has poor, or good self-reported sleep quality; however, it cannot tell us this is due to the  
62 experience of specific types of problems sleeping (e.g., due to insomnia, sleep apnea,  
63 nightmares etc.). Although there is evidence suggesting that those with IBD may experience  
64 specific types of problems sleeping more commonly, including symptoms of sleep apnea  
65 (Keefer et al., 2006), restless legs (Becker et al., 2018; Keefer et al., 2006), and nightmares  
66 (Ranjbaran et al., 2007); the conclusions that can be drawn are limited - in that findings are  
67 often reliant on single-item measures of specific problems sleeping, and/or small sample sizes  
68 leading to underpowered studies. Consequently, it is important that research also uses multi-  
69 item measures of specific sleep disturbances along with larger samples to draw more robust  
70 conclusions. Secondly, few studies have compared the problems sleeping seen in IBD to  
71 healthy controls (i.e., those without gastrointestinal diagnoses). Consequently, it is unclear  
72 whether both the type and magnitude of problems sleeping differ between those with, and  
73 without a diagnosis of IBD.

#### 74 **The present research**

75 The lack of research investigating specific types of sleep disturbance in IBD relative  
76 to healthy controls serves to inhibit two important avenues; i) the development and adaption  
77 of interventions to target specific sleep disturbances experienced by those with IBD as a route  
78 to improving IBD related outcomes; and ii) as has been recently suggested, the incorporation  
79 of sleep disturbance screening into the routine clinical management of IBD (Almedimigh et  
80 al., 2018; Kinnucan et al., 2013). The present research aims to address this by measuring the  
81 severity of multiple types of specific problems sleeping in those with diagnosis of IBD  
82 relative to healthy controls. We hope that doing so will provide a more comprehensive profile  
83 of the types of problems sleeping that are experienced by people with IBD, with each type  
84 generally having specific screening and treatment options.

## 85 **Materials and Methods**

### 86 **Participants**

87 The IBD group were recruited from three sources; (i) through an advertisement placed  
88 on a national IBD charity website in the UK (Crohn's & Colitis UK); (ii) from IBD specific  
89 online support groups; and (iii) from volunteer lists maintained by the research team. The  
90 healthy control group was recruited from two sources; (i) from volunteer lists maintained by  
91 the research team; and (ii) via a social media advertising campaign. Enrolment to the study  
92 began in May 2017, and concluded in November 2017. Prior to taking part in the present  
93 research, all participants were asked a number of screening and eligibility questions. To be  
94 eligible for the IBD group, participants were required to; (i) have a diagnosis of IBD; and (ii)  
95 be at least 16 years of age or older. To be eligible for inclusion in the control group,  
96 participants were required to; (i) have no diagnosis of any gastrointestinal disorder (e.g., IBD,  
97 Irritable Bowel Syndrome, coeliac disease etc.); and (ii) be at least 16 years of age or older.  
98 Participants not meeting these criteria, those who did not provide full informed consent, and  
99 those who did not start the online survey were excluded.

### 100 **Procedure**

101 Participants were invited to take part in an online study aiming to investigate the  
102 severity of problems sleeping in those with, and without, a diagnosis of IBD. All outcome  
103 measures were delivered anonymously online using Qualtrics, a web based survey hosting  
104 platform (Qualtrics, 2018). Participants first read an information sheet detailing aspects of the  
105 research before confirming eligibility via a series of screening items in line with the studies  
106 inclusion and exclusion criteria. If eligible, participants provided electronic consent to  
107 participate. The Research Ethics Committee based in the School of Health and Related  
108 Research (SchARR), University of Sheffield, granted ethical approval.

## 109 **Outcome Measures**

### 110 **Demographics**

111 All participants were asked to provide information relating to their age, gender, and  
112 whether they were currently receiving psychological therapy and/or medication for a mental  
113 health or sleep related problem. Participants in the IBD group were asked a number of items  
114 relating to their IBD, including their IBD diagnosis type (Ulcerative Colitis or Crohn's  
115 Disease), number of years living with an IBD diagnosis, whether they had ever undergone  
116 IBD related surgery, current and/or previous use of a stoma, and whether they were currently  
117 taking medication for their IBD.

### 118 **The Sleep-50 Questionnaire**

119 The Sleep-50 is a 50 item self-report instrument designed to measure symptoms of  
120 seven specific types of sleep disturbances (sleep apnea, insomnia, narcolepsy, restless legs,  
121 circadian rhythm disruption, sleepwalking, & nightmares), as well as factors influencing  
122 sleep (e.g., low mood, sleep environment not optimal, medication use), and the impact of  
123 sleep complaints of daily functioning (e.g., feeling tired on awakening, difficulty  
124 concentrating, worrying about sleep). Using a 4-point scale, participants are asked to rate the  
125 extent to which they endorse each item over the last 4-weeks, ranging from 'not at all'  
126 through to 'very much'. The Sleep-50 has been validated for use in both general population  
127 samples, and those with clinically defined sleep disorders, demonstrating a clear factor  
128 structure, high internal consistency, and good test-retest reliability (Spoormaker, Verbeek, van  
129 den Bout, & Klip, 2005).

### 130 **The Short Inflammatory Bowel Disease Questionnaire (SIBDQ)**

131 The bowel symptoms subscale of the SIBDQ (Jowett, Seal, Barton, & Welfare, 2001)  
132 was used as a proxy measure of disease symptom activity in the IBD group. The bowel  
133 symptom subscale of the SIBDQ asks participants to rate the extent to which they endorse

134 three items pertaining to the frequency of IBD symptoms on a 5-point scale, with lower  
135 scores indicating more frequent symptom activity. For example, participants are asked, “*How*  
136 *often in the last two weeks have you been troubled by pain in the abdomen?*”. The bowel  
137 symptoms subscale correlates strongly with several validated measures of disease activity  
138 (Jowett et al., 2001), including the Simple Clinical Colitis Activity Index (SCCAI; Walmsley,  
139 Ayres, Pounder, & Allan, 1998), and the Seo index (Seo et al., 1992), suggesting its valid use  
140 as a proxy measure of disease activity.

#### 141 **Approach to Analysis**

142 A one-way multivariate analysis of covariance (MANCOVA) was conducted to  
143 investigate the severity of seven specific types of sleep disturbances measured by the Sleep-  
144 50, as well as factors influencing sleep, and the impact of sleep complaints on daily  
145 functioning in the IBD group relative to controls. Where the MANCOVA demonstrated  
146 significant differences between the IBD and control groups in terms of the type of problem  
147 sleeping, a sensitivity analysis in the form of hierarchical linear regression (including only the  
148 IBD group) was conducted to investigate whether any IBD related characteristics were  
149 significantly associated with the sleep disturbance. G-Power 3.1 (Faul, Erdfelder, Lang, &  
150 Buchner, 2007) was used to determine the sample size. For the MANCOVA, based on a  
151 small-to-medium sized effect at 90% power, and a strict significance threshold of  $p < .001$ ,  
152 the desired total sample size is  $N = 560$ . Given that the hierarchical linear regression includes  
153 only the IBD group, a less conservative alpha level was set; based on a small-to-medium  
154 sized effect at 90% power, and a significance threshold of  $p < .05$ , the desired total sample  
155 size is  $N = 263$ .

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## Results

### Participants

Of the  $N = 498$  participants in the IBD group who started the study procedures,  $N = 409$  (82%) were included in the study, with  $N = 89$  (18%) excluded. Of those excluded in the IBD group,  $N = 9$  (10%) were under the age of 16,  $N = 7$  (8%) had no diagnosis of IBD,  $N = 22$  (25%) did not provide consent to take part, and  $N = 51$  (57%) did not start the online surveys. With regards to the control group,  $N = 472$  began the study procedures with  $N = 377$  (88%) included in the study. Of the  $N = 50$  (12%) who were excluded,  $N = 3$  (6%) were under the age of 16,  $N = 4$  (8%) had a diagnosis of IBD,  $N = 20$  (40%) had diagnosis of Irritable Bowel Syndrome (IBS),  $N = 10$  (20%) did not provide consent to take part, and  $N = 13$  (26%) did not start the online surveys. Figure 1 describes of the flow of participants through the study, while Table 1 presents the demographic and clinical characteristics of both groups.

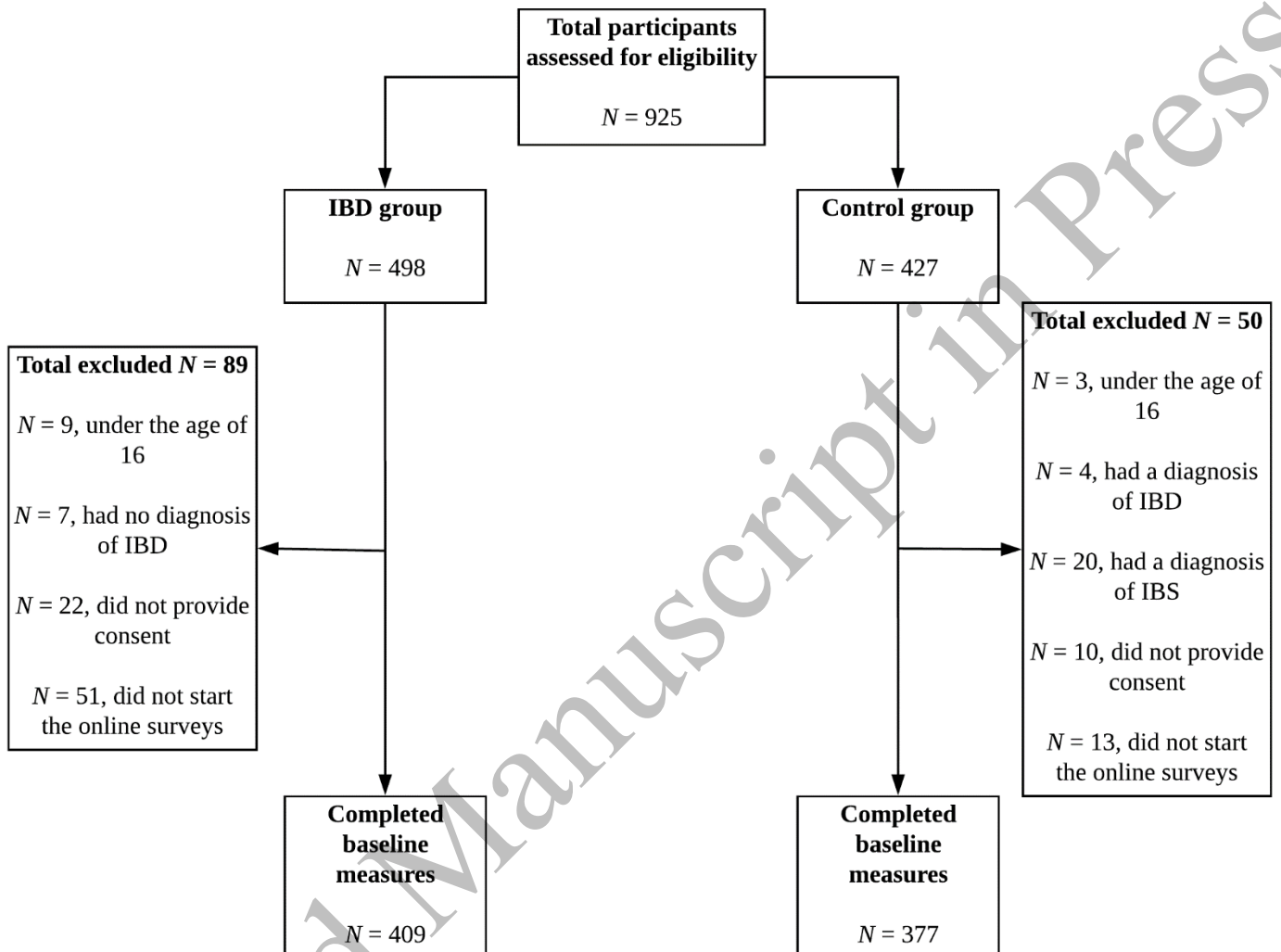
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169 **Figure 1**

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171 *A CONSORT Flow Diagram Showing the Flow of Participants Through the Study*

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173 **Table 1**174 *Baseline Sample Characteristics of the IBD and Control Group*

<b>Variable</b>	<b>IBD group (N = 409)</b>	<b>Control group (N = 377)</b>
<b>Age, M (SD)</b>	33.86 (11.57)	39.60 (14.51)
<b>Gender, N (%)</b>		
<i>Male</i>	74 (18%)	100 (27%)
<i>Female</i>	335 (82%)	277 (73%)
<b>Sleep medication use, N (%)</b>		
<i>Yes</i>	96 (23%)	17 (5%)
<i>No</i>	313 (77%)	360 (95%)
<b>Sleep therapy, N (%)</b>		
<i>Yes</i>	21 (5%)	3 (1%)
<i>No</i>	388 (95%)	374 (99%)
<b>IBD type, N (%)</b>		
<i>Ulcerative Colitis (UC)</i>	155 (38%)	-
<i>Crohn's Diseases (CD)</i>	254 (62%)	-
<b>Years with IBD diagnosis, M (SD)</b>	9.12 (8.52)	-
<b>Surgery for IBD, N (%)</b>		
<i>Yes</i>	172 (42%)	-
<i>No</i>	237 (58%)	-
<b>Current stoma, N (%)</b>		
<i>Yes</i>	58 (14%)	-
<i>No</i>	351 (86%)	-
<b>Previous stoma, N (%)</b>		
<i>Yes</i>	64 (16%)	-
<i>No</i>	345 (84%)	-
<b>Immunosuppressant use, N (%)</b>		
<i>Yes</i>	259 (63%)	-
<i>No</i>	150 (37%)	-

176 **Does specific sleep disturbance severity differ between groups?**

177 MANCOVA (controlling for age and gender) was used to examine whether the  
178 severity of specific sleep disturbances differed between those in the IBD group vs. the control  
179 group (see Table 2 for an overview of these analyses). There was a statistically significant  
180 multivariate difference between groups ( $F(9, 774) = 50.44, p < 0.001, \text{Eta}^2 = 0.08$ ), in that  
181 participants in the IBD group reported significantly more profound sleep disturbance than the  
182 control group. This effect was reflected in significantly more severe sleep disturbance across  
183 seven of the eight subscales measured by the Sleep-50, including symptom severity of; **sleep**  
184 **apnea** ( $F(1, 782) = 12.94, p < 0.001, \text{Eta}^2 = 0.02$ ), **insomnia** ( $F(1, 782) = 31.89, p < 0.001,$   
185  $\text{Eta}^2 = 0.04$ ), **narcolepsy** ( $F(1, 782) = 16.01, p < 0.001, \text{Eta}^2 = 0.02$ ), **restless legs** ( $F(1, 782)$   
186  $= 17.98, p < 0.001, \text{Eta}^2 = 0.02$ ), **nightmares** ( $F(1, 782) = 13.87, p < 0.001, \text{Eta}^2 = 0.02$ ),  
187 **factors influencing sleep** ( $F(1, 782) = 35.81, p < 0.001, \text{Eta}^2 = 0.04$ ), and the **impact of**  
188 **sleep disturbance on daily life** ( $F(1, 782) = 63.69, p < 0.001, \text{Eta}^2 = 0.08$ ). There were no  
189 significance differences between groups on the severity of **circadian rhythm disruptions**  
190 ( $F(1, 782) = 7.34, p = 0.01, \text{Eta}^2 = 0.01$ ), or **sleepwalking** ( $F(1, 782) = 4.48, p = 0.04, \text{Eta}^2 =$   
191  $0.01$ ).

192 **Table 2**193 *Descriptive Statistics and Between Group Comparisons of Sleep Disorder(s) in the IBD group vs. Controls*

Sleep outcome	IBD group (N = 409)		Control group (N = 377)		F	p	Eta <sup>2</sup>
	M	SD	M	SD			
<b>Sleep-50 total</b>	95.47	20.48	84.88	21.38	50.44	< <b>0.001</b>	0.08
<i>Sleep apnoea</i>	14.03	3.49	13.19	3.99	12.94	< <b>0.001</b>	0.02
<i>Insomnia</i>	20.33	3.49	17.99	5.57	31.89	< <b>0.001</b>	0.04
<i>Narcolepsy</i>	7.74	2.34	7.06	2.29	16.01	< <b>0.001</b>	0.02
<i>Restless legs</i>	6.59	2.47	5.87	2.41	17.98	< <b>0.001</b>	0.02
<i>Circadian rhythm disruption</i>	5.23	2.01	4.79	1.80	7.34	0.01	0.01
<i>Sleepwalking</i>	3.36	0.99	3.23	0.78	4.48	0.04	0.01
<i>Nightmares</i>	8.29	5.51	6.73	5.65	13.87	< <b>0.001</b>	0.02
<i>Factors influencing sleep</i>	11.09	2.71	9.94	2.50	35.81	< <b>0.001</b>	0.04
<i>Impact on daily function</i>	18.89	4.87	16.08	5.18	63.69	< <b>0.001</b>	0.08

194 *Note: M = mean, SD = standard deviation, p values in bold type represent statistically significant effects at p < 0.001 .*

**195 Clinical correlates of sleep disturbance in the IBD group**

196           Where there was a significant difference between the IBD and control group in the  
197 preceding analysis, a sensitivity analysis was conducted using only the IBD group to investigate  
198 potential clinical correlates of sleep disturbances. Table 3 presents the detailed results of this  
199 analysis; however, in short, none of the characteristics of the IBD group were associated with the  
200 experience of sleep apnoea ( $F(8, 375) = 0.61, p = 0.77$ ), narcolepsy ( $F(8, 375) = 0.46, p = 0.88$ ),  
201 or nightmares ( $F(8, 375) = 0.71, p = 0.68$ ). However, a higher IBD symptom activity as  
202 measured by the bowel symptom subscale of the SIBDQ was negatively associated with  
203 increased insomnia severity ( $\beta = -0.14, p = 0.01$ ), restless legs symptom severity ( $\beta = -0.14, p =$   
204  $0.03$ ), increased factors influencing sleep, ( $\beta = -0.15, p = 0.01$ ), and increased impact of sleep  
205 disturbances on daily function ( $\beta = -0.13, p = 0.01$ ). Furthermore, IBD diagnosis type was  
206 associated with the impact of sleep complaints on daily function ( $\beta = 0.14, p = 0.01$ ), with those  
207 diagnosed with Ulcerative Colitis reporting more daily impact.

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209 **Table 3**210 *Clinical Correlates of Specific Sleep Disturbances in the Inflammatory Bowel Disease (IBD)*211 *Group*

<b>Sleep problem</b>	<b><math>\beta</math></b>	<b><i>t</i></b>	<b><i>p</i></b>
<b>Sleep apnea</b>			
<i>Age</i>	-0.02	-0.31	0.75
<i>Gender</i>	-0.02	-0.40	0.69
<i>IBD type</i>	0.02	0.30	0.76
<i>Years with IBD</i>	-0.01	-0.09	0.93
<i>IBD surgery</i>	0.06	0.91	0.36
<i>Current stoma</i>	0.04	0.74	0.46
<i>IBD medication</i>	0.01	0.27	0.79
<i>IBD symptom activity</i>	-0.02	-0.44	0.66
<b>Insomnia</b>			
<i>Age</i>	-0.10	-1.62	0.11
<i>Gender</i>	-0.05	-0.91	0.36
<i>IBD type</i>	0.02	0.37	0.71
<i>Years with IBD</i>	0.05	0.79	0.43
<i>IBD surgery</i>	-0.07	-1.02	0.31
<i>Current stoma</i>	0.06	1.01	0.31
<i>IBD medication</i>	0.04	0.78	0.44
<i>IBD symptom activity</i>	-0.12	-2.21	<b>0.03</b>
<b>Narcolepsy</b>			
<i>Age</i>	-0.03	-0.55	0.59
<i>Gender</i>	0.02	0.43	0.66
<i>IBD type</i>	0.06	0.98	0.33
<i>Years with IBD</i>	-0.04	-0.65	0.52
<i>IBD surgery</i>	-0.05	-0.81	0.42
<i>Current stoma</i>	-0.03	-0.46	0.65
<i>IBD medication</i>	-0.05	-0.98	0.33

<i>IBD symptom activity</i>	-0.04	-0.65	0.51
<b>Restless legs</b>			
<i>Age</i>	0.04	0.75	0.45
<i>Gender</i>	0.02	0.31	0.75
<i>IBD type</i>	-0.01	-0.19	0.85
<i>Years with IBD</i>	-0.02	-0.24	0.81
<i>IBD surgery</i>	-0.01	-0.20	0.84
<i>Current stoma</i>	0.07	1.13	0.26
<i>IBD medication</i>	0.01	0.10	0.92
<i>IBD symptom activity</i>	-0.12	-2.22	<b>0.03</b>
<b>Nightmares</b>			
<i>Age</i>	0.01	0.19	0.85
<i>Gender</i>	0.04	0.76	0.45
<i>IBD type</i>	0.01	0.12	0.91
<i>Years with IBD</i>	-0.10	-1.53	0.13
<i>IBD surgery</i>	-0.11	-1.76	0.08
<i>Current stoma</i>	0.10	1.67	0.10
<i>IBD medication</i>	-0.02	-0.32	0.75
<i>IBD symptom activity</i>	0.06	1.16	0.25
<b>Factors influencing sleep</b>			
<i>Age</i>	-0.05	-0.81	0.42
<i>Gender</i>	-0.04	-0.80	0.42
<i>IBD type</i>	0.07	1.22	0.22
<i>Years with IBD</i>	0.07	1.11	0.27
<i>IBD surgery</i>	-0.06	-0.92	0.36
<i>Current stoma</i>	0.04	0.71	0.48
<i>IBD medication</i>	0.06	1.13	0.26
<i>IBD symptom activity</i>	-0.15	-2.70	<b>0.01</b>
<b>Impact on daily function</b>			
<i>Age</i>	0.02	0.35	0.73
<i>Gender</i>	-0.03	-0.60	0.55

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<i>IBD type</i>	0.14	2.56	<b>0.01</b>
<i>Years with IBD</i>	0.01	0.17	0.86
<i>IBD surgery</i>	-0.06	-0.99	0.32
<i>Current stoma</i>	-0.07	-1.13	0.26
<i>IBD medication</i>	0.01	0.26	0.79
<i>IBD symptom activity</i>	-0.13	-2.48	<b>0.01</b>

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212 *Note: p values in bold type represent statistically significant effects at  $p < 0.05$*

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**Discussion**

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The present research aimed to investigate the nature and magnitude of specific types of problems sleeping in those with IBD relative to a healthy control group (i.e., no gastrointestinal diagnoses). Our findings suggest that relative to controls, those with IBD reported significantly more severe symptoms of five of the seven sleep disturbances measured by the Sleep-50, including; sleep apnea, insomnia, narcolepsy, restless legs, and nightmares. Furthermore, those with IBD reported experiencing significantly more factors that are known to influence sleep (e.g., low mood, sleep environment not optimal, medication use), and a greater impact of sleep disturbances on daily life (e.g., feeling tired on awakening, difficulty concentrating, worrying about sleep). Interestingly, only the experience of insomnia, and the impact of sleep disturbances on daily life was associated with some clinical features of IBD. Greater insomnia severity was associated with more frequent IBD symptoms, whereas a diagnosis of Ulcerative Colitis was significantly associated with a greater impact of sleep disturbances on daily life.

The key finding reported in the present research is that those with IBD reported more severe experiences of a variety of specific problems sleeping, including; sleep apnea, insomnia, narcolepsy, restless legs, and nightmares, as well as more disruptions to factors known to influence sleep, and a greater impact of sleep disturbances on daily life. Although the majority of extant research reports the association between global sleep quality and IBD, the few studies that have examined specific types of problems sleeping are supported by the present research. For example, the findings reported here support previous research suggesting that those with IBD experience sleep disordered breathing (i.e., a core symptom of sleep apnoea, Keefer et al., 2006), restless legs (Becker et al., 2018; Keefer et al., 2006), and nightmares (Ranjbaran et al., 2007). As well as strengthening existing findings using a larger sample size, and a multi-item measure

236 *specific* problems sleeping, the findings reported here also extend previous work by reporting an  
237 increased severity of insomnia, and narcolepsy symptoms in the IBD group relative to controls.  
238 Although more research is warranted, these findings suggest that the routine care of those with  
239 IBD might consider incorporating assessments to screen for the presence a variety of specific  
240 types of problems sleeping.

#### 241 **Future directions**

242 It seems clear that problems sleeping are associated with IBD, and may even represent a  
243 core experience of IBD itself (Keefer et al., 2006). However, *how* problems sleeping are related  
244 to IBD, and the direction that best explains this association is currently unclear. Consequently,  
245 future research might seek to elucidate the mechanisms of action that can explain how problems  
246 sleeping can exert an effect on IBD related outcomes, using designs able to inform the direction  
247 of effect. Research that is well placed to disentangle the impact of mediators and the direction of  
248 association between sleep and IBD outcomes are those that employ longitudinal designs (i.e.,  
249 designs that measure variables over time, so that the temporal relationship between variables can  
250 be investigated), research that is currently lacking (for notable exceptions, see Ananthakrishnan  
251 et al., 2014; Ananthakrishnan et al., 2013; Graff et al., 2013; Uemura et al., 2016). Problems  
252 sleeping have been posited as a possible modifiable environmental risk factor that can adversely  
253 affect IBD outcomes. However, despite recent calls to screen for, and subsequently treat  
254 problems sleeping in those with IBD (Almedimigh et al., 2018; Kinnucan et al., 2013), there are  
255 relatively few guidelines to facilitate clinical decision making in this area (National Institute for  
256 Health and Care Excellence, 2015; Kinnucan et al., 2013). Therefore, future research might  
257 profitably seek to understand the barriers and facilitators to effective sleep management in  
258 routine IBD care, from both the patients', and healthcare professional's perspectives as a route to

259 developing effective guidelines to facilitate the detection and subsequent treatment of specific  
260 sleep disturbances in those with IBD.

### 261 **Limitations of the present research**

262 Firstly, the present study recruited participants based on a self-reported IBD diagnosis.  
263 Although recent research has demonstrated that self-reported diagnosis in online research has a  
264 high concordance rate with physician diagnoses (Kelstrup, Juillerat, & Korzenik, 2014; Randell  
265 et al., 2014), this should be taken into account when considering the present findings. Secondly, a  
266 large proportion of the participants from which the present findings are based are female. This is  
267 perhaps not surprising given that there is evidence to suggest that there is a greater prevalence of  
268 IBD in women when compared to men (Bernstein, Blanchard, Rawsthorne, & Wajda, 1999;  
269 Brant & Nguyen, 2008). Indeed, findings based on majority female participants are a common  
270 occurrence in the sleep-IBD literature (Ananthakrishnan et al., 2014; Ananthakrishnan et al.,  
271 2013; Graff et al., 2013), and in epidemiological research more broadly (Dunn, Jordan, Lacey,  
272 Shapley, & Jinks, 2004; Galea & Tracy, 2007; Smith, 2008). The large sample size in the present  
273 research does mitigate some of the effects of sample representativeness, and the analyses  
274 controlled the effects of gender (gender was not associated with outcomes). That being said, the  
275 gender distributions in the present research need to be taken into account when interpreting the  
276 findings.

### 277 **Conclusions**

278 The present research found that, relative to controls, those with a diagnosis of IBD  
279 reported significantly more severe experiences of sleep apnea, insomnia, narcolepsy, restless  
280 legs, and nightmares, as well as more factors that influence sleep, and a greater impact of sleep  
281 complaints on daily life. We recommend that future research should explore three possible

282 avenues; i) investigation of the barriers/facilitators to the effective management of problems  
283 sleeping in the routine care of those with IBD; ii) research aiming to elucidate the directional  
284 association between sleep and IBD related outcomes, as well as any mechanisms of action; and  
285 iii) the effectiveness and efficacy of interventions designed to improve sleep as a route to  
286 improving IBD related outcomes. We hope that the present research will highlight the nature and  
287 magnitude of problems sleeping in those with IBD, and facilitate more research in this area.

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