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# BMJ Open

## Patients' experiences of adapting to ulcerative colitis to try to live a 'normal' life

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Manuscripts

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For peer review only

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3 26 **ABSTRACT**  
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8 28 **Objective**  
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10  
11 29 To provide a framework that is able to categorise whether patients are able to adapt to and  
12  
13 30 lead a 'normal' life with ulcerative colitis (UC) and to detail the factors that influence this.  
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16 31  
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18 32 **Design**  
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20  
21 33 Qualitative research study using in-depth semi-structured interviews.  
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24 34  
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26 35 **Setting**  
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28 36 Four clinical sites in the West and East Midlands regions of England.  
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31 37  
32

33 38 **Participants**  
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35  
36 39 28 adult patients diagnosed with UC between 1 and 22 years.  
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39 40  
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41 41 **Results**  
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43 42 Medication was rarely sufficient for patients to adapt to UC and live as 'normal' a life as  
44  
45 43 possible. Virtually all patients tested and adopted non-medical adaptation methods to improve  
46  
47 44 physical and psychological wellbeing, to help them carry on working, and to prevent  
48  
49 45 embarrassment. In addition, some patients benefited from outside support, providing them  
50  
51 46 with practical, emotional, and/or financial help. In conjunction with adaptation strategies and  
52  
53 47 the time to adapt, this meant that some patients with severe clinical disease were able to  
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3 48 maintain a sense of normality in life. Patients reported that clinicians were not always  
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6 49 receptive to discussion of the broader context of life with UC.  
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## 10 51 **Conclusions**

11  
12  
13 52 Patients' experience of UC and their ability to adapt in order to maintain a sense of normality in  
14  
15  
16 53 life is a complex interplay of symptoms, adaptation strategies and outside support. Over time  
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18  
19 54 patients test out a variety of non-medical adaptation strategies. Awareness of this may help  
20  
21 55 clinicians and researchers to understand patients' views on the role of medical and other  
22  
23 56 therapies. Further research around the utility of this framework in clinical practice and  
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26 57 research is now required.  
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29 58

## 30 59 **Strengths and limitations of this study**

- 31  
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33 60 • This study is an in-depth participant-focused qualitative study providing rich and detailed  
34  
35 61 accounts of patients' experiences of living with and adapting to UC.  
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38 62 • This is the first detailed analysis that has attempted to categorise whether patients are able  
39  
40 63 to adapt to and lead a 'normal' life with UC, and also to detail the factors that influence  
41  
42 64 this.  
43  
44  
45 65 • The semi-structured interviews provided patients the opportunity to talk about their  
46  
47 66 experience to someone outside of their clinical team.  
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51 67 • The research is cross-sectional in nature, limiting the potential to observe the temporal  
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53 68 components of adaptation over time.  
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4 69 • The patients interviewed were participating in a pilot trial, which means that the range of  
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6 70 patients was influenced by the trial eligibility criteria.  
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11 72 **Funding**

12  
13 73 This work was supported by a grant from the Research for Patient Benefit (RfPB) programme of  
14  
15  
16 74 the National Institute for Health Research (NIHR) (grant number - ISRCTN56523019).  
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18 75  
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21 76 **Competing interests**

22  
23 77 The authors confirm that they have no conflict of interest to disclose.  
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6 81**INTRODUCTION**

82 Ulcerative colitis (UC) is a form of chronic inflammatory bowel disease (IBD) which effects the  
83 large bowel. Over 145,000 people in the UK<sup>1</sup> and 900,000 in the USA<sup>2</sup> are living with UC. The  
84 condition is most prevalent in Northern Europe and North America, although the number of  
85 people affected by UC is increasing recently in developing countries.<sup>3</sup> There is also an  
86 increasing incidence of UC among younger patients.<sup>4</sup> Around 40% of patients will experience a  
87 relapse annually, with between 20% and 30% requiring total colectomy in their lifetime.<sup>5,6</sup>  
88 Reducing relapse rates and disease progression is a priority for patients.<sup>7</sup> Ulcerative colitis has  
89 been shown to have a significant negative impact on Health-Related Quality of Life (HRQoL).<sup>8</sup>  
90 Whilst many patients' lives are severely disrupted as, for example, the disease affects their  
91 ability to work as well as their social and family life,<sup>8-11</sup> these impacts are not always directly  
92 correlated, from a clinical perspective, with disease activity and severity of symptoms.<sup>12</sup>  
93 Patients with mild clinical disease can experience significant impacts on HRQoL and  
94 psychological morbidity, whilst some with apparently severe disease activity seem to 'cope'  
95 relatively well.

96  
97 Commentators have argued that often the focus of the medical management of IBD is too much  
98 on acute episodes, not necessarily reflecting the chronicity of IBD and therefore the overall  
99 patient experience of disease over time.<sup>13</sup> Understanding more about living with IBD can help  
100 to highlight the role that medical and surgical management plays. The patient perspective on



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3 101 living with UC may sometimes be difficult for clinicians to interpret as they may underestimate  
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6 102 or overlook the overall effects of disease on patients' lives.<sup>8</sup>

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11 104 Qualitative research is well placed to describe and understand patients' views on disease and  
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13 105 treatment.<sup>14</sup> Within IBD and UC there is a small but informative body of qualitative research  
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16 106 relevant to these issues and work to date has described patients' perspectives on the impact of  
17  
18 107 IBD; of the physical symptoms, and broader issues, for example, on work, lifestyle, daily  
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20  
21 108 activities, social life, and psychological well-being.<sup>8-11,15-20</sup> Research has suggested that patients  
22  
23 109 are engaged in a 'fight' for some sort of health-related normality and that achieving a 'new  
24  
25  
26 110 normal' is their ultimate goal.<sup>15</sup> Trying to live as 'normal' a life as possible is something that  
27  
28 111 patients reflect upon when they talk about life with IBD.<sup>12</sup> This body of research describes  
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30  
31 112 patients' views on how their lives are affected by IBD and shows that adaptation (i.e. a desire  
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33 113 for normality) is an overriding concern. However, to date nobody has provided a clear  
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36 114 framework to help understand normality and adaptation in UC.

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41 116 The aim of this paper is therefore twofold; (1) to provide a framework that is able to categorise  
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43 117 whether patients are able to adapt to and lead a 'normal' life with UC and (2) to detail the  
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46 118 factors that influence this.

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## 51 120 **METHODS**

### 53 121 **Setting and study design**

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3 122 Participants were recruited from four hospitals in the West and East Midland regions of England  
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5  
6 123 and were taking part in the National Institute for Health Research (NIHR) Research for Patient  
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8 124 Benefit-funded ACCURE-UK trial.<sup>21</sup> This randomised external pilot trial was exploring the  
9  
10 125 feasibility of a multi-centre randomised controlled trial (RCT) of therapeutic appendicectomy  
11  
12 126 for the treatment of UC (intervention arm) in addition to standardised medical therapy (control  
13  
14 127 arm). The trial included integrated qualitative research, the main aim of which was to explore  
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16 128 acceptability of the trial and understand this within the context of patients' everyday lives with  
17  
18 129 UC.  
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### 24 131 **Sampling and recruitment**

25  
26 132 We recruited a diverse sample (age, gender, time since diagnosis) of patients from both arms of  
27  
28 133 the pilot RCT. Clinical staff initially discussed the qualitative research with patients. With  
29  
30 134 consent, the contact details of patients expressing an interest were passed to the researcher  
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32 135 conducting the interviews (CM), who then took informed consent prior to interview.  
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### 41 137 **Data collection**

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43 138 Semi-structured one-to-one interviews were conducted by CM between randomisation and  
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45 139 surgery for those allocated to intervention arm, and shortly after randomisation for those in the  
46  
47 140 control arm. CM is a non-clinical trained qualitative researcher independent from participants'  
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49 141 clinical care and the day-to-day trial management. This was clearly communicated to  
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51 142 participants. Participants were asked to select a convenient time and place for interview. Most  
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3 143 chose to be interviewed at home, although a small number of interviews were conducted on  
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6 144 hospital or university premises, or by telephone.  
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11 146 The interview schedule was informed by the existing literature and consultation with the wider  
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13 147 research team. It included discussion of patients' views and experience of life with UC since  
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16 148 initial diagnosis: their symptoms, their flare ups and their impacts, their medical treatment, and  
17  
18 149 their perspectives on adaptation to UC. In addition, a section of the interview focused on  
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20  
21 150 participants' perspectives on the RCT and trial processes (data not reported here). Interviews  
22  
23 151 were conducted in a participant-focused open-ended manner. After initial piloting, data  
24  
25  
26 152 collection and analysis took place iteratively. This continued until the research team judged  
27  
28 153 that the data and sample had sufficient depth and breadth to address initial research  
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31 154 questions.<sup>22</sup> Field notes were kept after the interviews to record factors that might have  
32  
33 155 influenced the conduct and the analysis of the interviews.  
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36 156  
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38 157 **Data analysis**  
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41 158 All interviews were audio-recorded and transcribed verbatim by a specialist external  
42  
43 159 transcription company. Data were analysed thematically and managed using Computer-Aided  
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46 160 Qualitative Data Analysis Software (CAQDAS), NVivo10. The analysis was informed by the  
47  
48 161 Framework analytical approach.<sup>23</sup> Firstly, interview transcripts were reviewed several times and  
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51 162 open coding was undertaken. These codes were then reviewed and categorised and the  
52  
53 163 dataset indexed. Categories were refined into overarching themes from descriptive accounts of  
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56 164 the data. Final analysis and explanation was facilitated by use of a typology and associative  
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3 165 analysis using charting. The analytic typology is described in more detail below. A sample of  
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6 166 interviews were coded by an independent researcher during initial coding. The final analysis  
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9 167 and interpretation were discussed amongst the research team, and with one patient who took  
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11 168 part in the interviews.

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### 15 16 170 **Analytic typology**

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18 171 During analysis we have applied a typology devised from qualitative data gathered with  
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21 172 patients with rheumatoid arthritis, another chronic inflammatory disease of relapsing remitting  
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23 173 nature.<sup>24</sup> A typology is a classification system that consists of categories that describe different  
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25  
26 174 types of a phenomenon of interest; here adaptation to life with UC and the ability to attain a  
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28  
29 175 new sense of normality. Typologies are sometimes used to categorise observations in  
30  
31 176 qualitative data.<sup>25</sup>

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33  
34 177 In addressing our first research aim we have categorised participants into two types (see Table  
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36 178 1 & Table 2), one of broadly positive experience and adaptation to UC ('the normal life') and  
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38  
39 179 one of negative experience and non-adaptation ('the non-normal life'). This typology  
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41 180 encompasses patients' reactions to their illness, their attempts to adapt to it, and success or  
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44 181 failure in this. Of note, these are not static categorisations; patients may move between them,  
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47 182 over time, and as a consequence of changing circumstances. We have used the accounts given  
48  
49 183 by participants during the interviews to assign them to these two broad categories, at the time  
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51 184 of the interview, and at time points since diagnosis.

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56 186 Insert Table 1  
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**188 ETHICAL CONSIDERATIONS**

189 Ethical approval for the ACCURE-UK trial was granted from the North East Tyne and Wear South  
190 Research Ethics Committee, REC number 14/NE/1143.

191

**192 RESULTS**

193 The following analysis is based on data from interviews with 28 patients (Table 2), which lasted  
194 between 22 and 58 minutes; 16 women and 12 men aged between 18 and 57; diagnosed with  
195 UC between 1 and 22 years. All were in remission at the time of interview but had experienced  
196 a disease relapse within the preceding 12 months (RCT eligibility criteria). All but one were on  
197 medical therapy, with three having taken biologic therapies, such as infliximab and  
198 adalimumab. One patient had decided to discontinue all medical therapy due to side effects.  
199 None had undergone any colonic surgery previously. There was no withdrawal.

200

201 Insert Table 2

202

203 Findings are presented as follows:

- 204 • the normality types experienced and described by our participants
- 205 • their adaptation strategies and intended purpose
- 206 • the outside support to adaptation and;
- 207 • how these factors interact with symptoms to influence the ability of a patient with UC to  
208 lead a normal life

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6 210 **Participants' descriptions of normal and non-normal life since diagnosis**

7  
8 211 Our analysis of patients' accounts suggests that at the point of interview, 12 of the 28  
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10 212 participants in this sample could be categorised as experiencing some form of normal life with  
11  
12 213 UC. There was no clear relationship between the length of time since diagnosis and the type of  
13  
14 214 normality they were experiencing at the time of the interview. At diagnosis, all participants had  
15  
16 215 described a period of non-normal life with significant disruption due to disease activity and  
17  
18 216 symptoms. Some also talked about a need to understand and acknowledge the significance of  
19  
20 217 the diagnosis itself. Participants suffered from intrusive symptoms (stomach cramps, bleeding,  
21  
22 218 more frequent bowel movements) and in many cases it took several months to receive a  
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24 219 definitive diagnosis and treatment, with several patients ending up being admitted to hospital.  
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26 220 As a result, they had to take time off work and were not able to carry on with their daily  
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28 221 activities:  
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38 223 *"Diagnosed in October. We were actually away in Spain when I had the flare up, and I*  
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40 224 *was in hospital in Spain for a week, and they did all the tests there, then when I got back*  
41  
42 225 *to England they did it all again in October. I was due to go in for the camera, and when I*  
43  
44 226 *got there they said that I'd got so weak that they wouldn't be able to do it, but they kept*  
45  
46 227 *me in, and obviously I was in hospital then for three weeks, or nearly four weeks I believe*  
47  
48 228 *it was at the time"* (Patient 18)  
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3 230 Following an initial period of disruption and non-normal life around the time of diagnosis  
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6 231 participants' accounts vary, with some seemingly not having attained or regained any sense of a  
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8 232 normal life. Others had managed to do so, some temporarily. Only three patients described a  
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10 233 period where they felt that they had been relatively unaffected as their symptoms were largely  
11  
12 234 controlled by medication, such that they were able to carry on life without much perceived  
13  
14 235 impact. For example, one male participant who was diagnosed in 2002 talked about not having  
15  
16 236 a flare up whilst managing UC for the first five years with medication. None of the participants  
17  
18 237 indicated that medication had dealt with all of their symptoms to the extent that life was the  
19  
20 238 same as before the onset of disease.  
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#### 240 **Participants' descriptions of adaptation strategies and their intended purpose**

241 During the interviews all participants described attempts to adapt to their condition, and all but  
242 two participants actively tested or adopted approaches that were additional to medical  
243 therapies. We have categorised the adaptation strategies described according to their  
244 intended purpose. Most commonly participants aimed to achieve four things (Table 3):  
245

246

- 246 • To improve physical wellbeing
- 247 • To improve psychological wellbeing
- 248 • To carry on working
- 249 • To prevent embarrassment

250

251 Insert Table 3

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6 253 Improve physical wellbeing

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8 254 This category describes participants' strategies to reduce physical symptoms and the frequency  
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10 255 of UC flare ups, and also to do so by addressing perceived triggers of flare ups. The physical  
11  
12 256 symptoms were a very important part of the great majority of patients' accounts, as they made  
13  
14 257 them extremely fatigued:

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17  
18 259 *"Just draining, not tired, not sleepy, just drained. [Name] knows what I'm like, by the*  
19  
20  
21 260 *time I've been five times and I've just got no energy, just no energy to do anything, and I*  
22  
23 261 *just the best thing is just to give into it. I say to [name], you're going to have to count me*  
24  
25 262 *out for the rest of the day, and just give into it"* (Patient 21)

26  
27 263

28  
29 264 The most common adaptation approach in this category was medication, with all but one  
30  
31 265 participant taking regular medication to improve physical wellbeing. The one participant, who  
32  
33 266 had ceased taking medication due to side effects, reported that smoking helped to reduce  
34  
35 267 symptoms. During the interviews it was clear that there were varied perspectives on whether  
36  
37 268 medication was 'working'. Some reported that medication was effective and others that it was  
38  
39 269 not. Some participants were unsure as to how much it helped:

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42  
43 271 *"I don't notice any effect with the anti-inflammatories (...) It generally doesn't keep it*  
44  
45 272 *[UC] away, because like I say I can be fully recovered, go nine/ten months of the year*  
46  
47 273 *whilst taking anti-inflammatories every day, and still go into a flare up. But whether if I*

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3 274 *didn't take them I don't know if I'd go into a flare up quicker. So I don't know" (Patient*  
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6 275 1)

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11 277 Another common adaptation approach to improve physical wellbeing was to change diet. As  
12  
13 278 with other adaptation approaches, this was often a trial and error strategy with the aim to  
14  
15 279 establish which foods tended to worsen symptoms or trigger flares. Some people reported  
16  
17 280 keeping a food diary for several weeks or months to identify patterns in their food intake and  
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19 281 symptoms:  
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23 282  
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25  
26 283 *"When I came out of hospital for about a month I kept a list of all the food I'd eaten*  
27  
28 284 *every day and what I'd drank, so that if I went into a flare up I could look back and say*  
29  
30 285 *maybe it was that, so I'll try it one more time and if it happens again I'll not eat or drink*  
31  
32 286 *that again" (Patient 10)*  
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36 287  
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38 288 Other adaptation strategies in this category include the use of complementary therapies (e.g.  
39  
40 289 acupuncture or hypnotherapy), exercise, yoga, relaxation courses to avoid triggers (stress), and  
41  
42 290 the pacing of activities to find a balance between symptoms and the ability to do things.  
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45

#### 46 291 47 48 292 Improve psychological wellbeing

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51 293 When discussing issues pertaining to psychological wellbeing several participants stated that  
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53 294 they have a positive and proactive outlook on life with UC. We believe that this signals  
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55 295 acceptance that the disease was not going to go away, and describes an associated attitude and  
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3 296 approach to living with it. This was sometimes evident in discussions about the need to ‘soldier  
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6 297 on’ and maintain some or all of the activities that participants pursued prior to diagnosis, such  
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8  
9 298 as playing sports, going out, and going on holiday. Often, similar to other adaptations, this  
10  
11 299 would involve a process of testing the boundaries of what was possible and finding a balance  
12  
13 300 between the desire to keep going and the potential negative (e.g. physical) consequences of  
14  
15 301 doing too much. For example, Patient 19, a 42 year old woman first diagnosed in 2003  
16  
17 302 described how, over the years, she adapted her activities to have more control of her condition,  
18  
19 303 but was keen not to be a ‘victim’, which she likened to being ‘too depressive’:  
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25  
26 305 *“I just refuse to give up and not do anything, and I know that the exercise is good for me.*  
27  
28 306 *But equally I know that doing too much exercise is bad for me, because it will make me ill*  
29  
30 307 *and run down (...) refusing to not do anything and be a victim and just sit at home doing*  
31  
32 308 *nothing, because that’s just too depressing to even think about isn’t it?” (Patient 19)*  
33  
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37  
38 310 Specific activities that were adopted by participants in an attempt to improve psychological  
39  
40 311 wellbeing included attending mindfulness and relaxation courses, and also yoga.  
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43 312

#### 44 45 313 Carry on working

46  
47 314 Being able to maintain a working life was expressed as a key concern by the majority of our  
48  
49 315 participants. The main strategy in order to carry on working was reducing working hours,  
50  
51 316 because of fatigue (one of the most commonly reported physical symptoms), a lack of  
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3 317 concentration and the need to constantly be near toilets. Spending less time in work meant  
4  
5  
6 318 that participants had more time for themselves to rest at home:  
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8 319  
9  
10 320 *“There’s certain things I can’t do at work, like I don’t do playground duty, because that*  
11  
12 *way I get an extra break, I don’t teach PE, it just wears me out really, it is quite a physical*  
13 321 *job. I’ve had to reduce my days as well, I did work three days a week before I was*  
14  
15 322 *diagnosed, and now I only work two”* (Patient 6)  
16  
17 323  
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21 324

22  
23 325 Participants who reduced their working hours found themselves to be more efficient at work.  
24

25  
26 326 However, this had a financial impact, placing burden on participants and their families.  
27

28 327 Other strategies to maintain working included rearranging working patterns (e.g. working only  
29  
30 328 in the afternoon as symptoms were worse in the morning; spreading working hours throughout  
31  
32 329 the week), changing jobs to something less demanding, and getting up earlier in the morning to  
33  
34 330 have more time to deal with the symptoms and be ready in time for work.  
35  
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38 331

39  
40  
41 332 Prevent embarrassment  
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43 333 Avoiding and preventing the embarrassment potentially caused by UC was a key theme in the  
44  
45 334 data. This very often restricted participants in their daily life, for example, with the fear of  
46  
47 335 being embarrassed by not being able to find toilets when needed:  
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3 337 *"I don't go out as much as I did before, and when I go out I'm very nervous, first thing I*  
4  
5  
6 338 *do a check where is the nearest toilet even if I don't need it, and some days if my friends*  
7  
8 339 *want to go out or do something I might be too fatigued"* (Patient 4)  
9  
10

11 340  
12  
13 341 One strategy employed to prevent embarrassment was situational avoidance with some  
14  
15  
16 342 participants reporting not going out or not going to places where toilets are not readily  
17  
18 343 available. Whilst such avoidance may be perceived as being effective in preventing  
19  
20  
21 344 embarrassment, in turn it could result in feelings of isolation:  
22

23 345  
24  
25  
26 346 *"Well because I've been having so many flare ups and been unwell a lot I don't have so*  
27  
28 347 *much of a social life now, and every time I try and plan things in I end up being ill a lot*  
29  
30  
31 348 *and having to cancel all the time, so I stopped making forward plans now to be honest,*  
32  
33 349 *because if there are things a few months away I just say to friends that I have to let you*  
34  
35  
36 350 *know at the time, because I never know what my health is going to be like. So it has had*  
37  
38 351 *quite an impact socially. It can be a bit isolating as well, that's a bit difficult"* (Patient 8)  
39  
40

41 352  
42  
43 353 Other participants discussed having to carefully plan, such as for nights out, around the location  
44  
45  
46 354 of the toilets, to limit the frequency of their social outings, or to try to plan them during  
47  
48 355 remission periods. Finally, one patient admitted being able to go out because he was wearing  
49  
50  
51 356 nappies, which meant he was not as restricted by the location of toilets.  
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3 358 Personal research, including participation in disease-specific internet forums and social media  
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5  
6 359 was described as contributing to each of the aims associated with adaptation strategies that  
7  
8  
9 360 were tested by patients:

10 361  
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12  
13 362 *“It’s just a Facebook group of everybody who has got Crohn’s and colitis really, it’s a*  
14  
15  
16 363 *group where you could obviously speak to other people about your condition. There’s*  
17  
18 364 *quite a lot of support on there, and it has been mentioned, and so there’s obviously*  
19  
20  
21 365 *people already know already. There seems to be a lot of support for anything,*  
22  
23 366 *awareness of disease, and look at ways of improving the condition” (Patient 3)*  
24  
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26 367

27  
28 368 **Outside support to adaptation**

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30  
31 369 Some patients spoke about the influence of outside support in enabling life and adaptation to  
32  
33 370 UC. Such support was not necessarily asked for or actively sought by participants but  
34  
35  
36 371 nevertheless helped them live and manage UC on a day-to-day basis. They provided an  
37  
38 372 invaluable source of social support for several participants.  
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41 373

42  
43 374 The main support evident in the data were:

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46 375
  - Help from parents/close family members (practical, emotional, and financial)
- 47  
48 376
  - Help from a partner and/or children (practical and emotional)
- 49  
50  
51 377
  - Help from friends (practical and emotional)
- 52  
53 378
  - Help from employer/workplace (practical)

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3 380 Support from parents and other close family members included moving closer to participants or  
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6 381 having them live with them in order to help with day-to-day tasks e.g. the school run,  
7  
8 382 household chores, and give them financial help:  
9

10 383  
11  
12  
13 384 *“My parents have moved house to be nearer (...) But they rushed the move because I was*  
14  
15  
16 385 *poorly, they actually moved while I was in hospital, because while I was in hospital they*  
17  
18 386 *were staying here for half the week to have my boys, because when I was in hospital*  
19  
20  
21 387 *both my boys were preschool age, they were two and four, so obviously someone had to*  
22  
23 388 *have them.” (Patient 6)*  
24

25 389  
26  
27  
28 390 Participants also often discussed the practical and emotional support provided by their partners  
29  
30  
31 391 and children:  
32

33 392  
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35  
36 393 *“Luckily my daughter is quite mature for her age, because she’s only 11, but she does*  
37  
38 394 *understand, and she’s quite good, and she will help me, and if I need help she is always*  
39  
40  
41 395 *there, and make me a cup of tea and little things like that. So yes quite lucky in that*  
42  
43 396 *respect.” (Patient 15)*  
44

45 397  
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47  
48 398 Finally, work managers and the workplace often offered practical support to patients, mainly by  
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51 399 providing flexible working hours, helping them to attend hospital appointments or deal with the  
52  
53 400 impact of symptoms:  
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3 402 *“Work have been pretty good, been really good with allowing me time off for*  
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6 403 *appointments and things.”* (Patient 23)  
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10  
11 405 One patient described how his workplace had recognised UC as a disability, and that this was  
12  
13 406 invaluable in providing the means to accommodate the impacts of the disease e.g. by taking  
14  
15  
16 407 time off work for hospital appointments or because of symptoms.  
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18 408

19  
20  
21 409 **How symptoms, adaptation strategies and outside support interact to influence adaptation**  
22  
23 410 **and the ability to live a normal life with UC**  
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25  
26 411 Whether patients are able to maintain or regain a sense of a normal life with UC appears to be  
27  
28 412 a complex interplay between disease activity and symptoms, the impacts of these, attempts to  
29  
30  
31 413 adapt, and outside support (Figure 1). Those patients who, overall, describe and judge their  
32  
33 414 disease activity to be mild were also more likely to indicate that they were able to regain a  
34  
35  
36 415 sense of normality. Most, but not all of these patients, thought that their medication was  
37  
38 416 successful in helping them control symptoms and impacts. All but one had adopted some  
39  
40  
41 417 adaptation strategies and half described the positive influence of outside support. However,  
42  
43 418 several patients who described mild disease did not convey a sense of a normal life. Most of  
44  
45  
46 419 these had been diagnosed relatively recently, related uncertainty about the effectiveness of  
47  
48 420 their medication, were testing out adaptation strategies and were less likely to describe the  
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50  
51 421 positive influences of outside support.  
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56 423 Insert Figure 1  
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6 425 Those patients that described moderate or severe disease activity, symptoms and impact, also  
7  
8  
9 426 frequently described a non-normal life. Again, several of these patients were recently  
10  
11 427 diagnosed, and were less certain about the effectiveness of medication in controlling disease  
12  
13 428 activity and symptoms. Only one of these patients, diagnosed over 10 years prior to interview  
14  
15  
16 429 detailed a long period of normality whilst medication controlled symptoms and prevented flare  
17  
18  
19 430 ups. More recently, with frequent flares this patient described her life as a 'rollercoaster' with  
20  
21 431 periods of severe disruption (flare ups) and intervening remission:  
22

23 432  
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25  
26 433 *"It is a bit like a rollercoaster, there's like it can be relatively stable for a while, but a flare*  
27  
28 434 *to me is when I start to lose blood and the urgency starts to creep up, and I find it*  
29  
30  
31 435 *difficult to like I say get out of the house in the morning and I have to use the toilet*  
32  
33 436 *frequently at work, or if I'm out, and they're specifically my flare up symptoms, and it's*  
34  
35  
36 437 *usually always with passing blood as well, and like I said probably about three of those*  
37  
38 438 *where I've been really bad over the past 12 months"* (Patient 3)  
39

40  
41 439  
42  
43 440 In contrast, four patients whom we interviewed, despite perceptions of more severe disease  
44  
45  
46 441 and flare ups, talked about life with UC in a manner concordant with regaining a sense of a  
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48  
49 442 normality. All but one had lived with UC for over 10 years and whilst they were unsure about  
50  
51 443 the effectiveness of their medication in controlling symptoms and flare ups, the use of  
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54 444 adaptation strategies and descriptions of positive outside support suggested that over time  
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3 445 they had been able to adapt to a life accommodating UC. For example, patient 19 adapted her  
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6 446 working hours to be less tired:

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10  
11 448 *"I also changed my hours, when I had my [previous/most severe] flare up three years*  
12  
13 449 *ago, I do 22 hours, and I used to do it in three days, so I would come in at half eight, and*  
14  
15 450 *eight o'clock in the morning, and I wouldn't finish until half four, I would have half an*  
16  
17 451 *hour for lunch. After I was last ill it was easy for me to change my hours, and I do the*  
18  
19 452 *same hours, but instead of doing it in three long days I do four short days, because for*  
20  
21 453 *me it's just easier, so then when I start to get tired I think well I'm going home mid-*  
22  
23 454 *afternoon, which is why I finish at half two, because it's easier for me physically to cope*  
24  
25 455 *with that, and mentally it's much easier"* (Patient 19)  
26  
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28  
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31 456

32  
33 457 Another participant described how his wife had been key in providing emotional and practical  
34  
35 458 support to help with adaptation:

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38  
39 459 *"I think the physical support, having somebody to lean on, you don't realise it at the time*  
40  
41 460 *when you're on your own that you've just got... obviously got family around you but*  
42  
43 461 *nobody directly in your life, in your house. I think just that moral and physical support*  
44  
45 462 *there is a help, every little helps, it's only a small percentage, it's a definite help"* (Patient  
46  
47 463 26)  
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54 465 **Time**  
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3 466 Participants' accounts and descriptions of attempts to adapt to UC since diagnosis demonstrate  
4  
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6 467 that this is an iterative and ongoing process of trial and error. People test the boundaries of  
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9 468 abilities and the role of adaptation methods and may take time to gain the necessary  
10  
11 469 facilitators to adaptation, and also to reach a point of acceptance of the disease or not.  
12  
13 470 Similarly, the role of medical therapies in improving physical wellbeing is often reported as  
14  
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16 471 being tested iteratively over time in collaboration with healthcare professionals. Finally,  
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19 472 circumstances may change over time, such as the frequency and severity of flares.  
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## 22 23 474 **DISCUSSION**

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26 475 To our knowledge, this is the first paper in UC and the IBD sphere to propose a framework of  
27  
28 476 normality (Figure 1) to categorise and understand patients' overall experience of life with the  
29  
30  
31 477 disease, and the factors that influence adaptation to it. The concept of disease-related  
32  
33 478 normality helps us to think about how disease impacts on patients holistically; the interplay of  
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36 479 physical symptoms; the consequences for daily life; and how patients see themselves and their  
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39 480 lives as a result. It shows how disease can be a disrupting life experience (the 'non-normal  
40  
41 481 life'), and how patients approach adaptation and whether, broadly speaking, they are  
42  
43 482 successful in this (the 'normal-life'). In the absence of cure, disease symptoms, adaptation  
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45  
46 483 strategies and outside support cumulate to influence patients' views on life with the disease.  
47  
48  
49 484 This can change over time, with acceptance of the disease and need to adapt, and with  
50  
51 485 changing circumstances, such as treatment, disease progression and the presence or absence of  
52  
53 486 outside support.  
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3 488 For patients with UC to be able to live a 'normal life', traditional medical management is likely  
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6 489 to be important but as highlighted in this sample, may be insufficient on its own. The majority  
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8  
9 490 of patients described other adaptation methods that they felt were required, that they had  
10  
11 491 tried and tested, or were in the process of testing. These methods aimed to achieve different  
12  
13 492 but interrelated things; physical and psychological wellbeing; the ability to carry on working and  
14  
15  
16 493 to prevent embarrassment. There may not be good evidence that the aims of the adaptation  
17  
18 494 strategies can be achieved by the specific methods adopted by patients. As we have described,  
19  
20  
21 495 patients themselves often actively reflect on the efficacy of their actions, for example, in  
22  
23 496 monitoring and adjusting diet to influence physical wellbeing. Despite this, the trial and error  
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25  
26 497 adoption of different strategies may in itself be important as part of a process of  
27  
28 498 accommodating disease and being active in doing so. Research in diabetes<sup>26</sup> has proposed that  
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30  
31 499 such actions are important for young people in attempting to 'master' their disease, and recent  
32  
33 500 research around normality in cancer survivorship<sup>27</sup> has also indicated that the act of doing  
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36 501 things is important in its own right regardless of the outcome of the action itself.  
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41 503 It was also clear that adaptation and normality were specific to the individual, meaning  
42  
43 504 different things to different people. Re-formulating identity and sense of self with disease is  
44  
45  
46 505 crucial for adaptation. Loss of sense of self has been identified as integral to chronic disease  
47  
48 506 experience generally,<sup>28</sup> and other researchers interested in normality in IBD have also observed  
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50  
51 507 that identity influences views on normality.<sup>9,15,17</sup> For a normal life to be achieved, the disease  
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53  
54 508 and its impacts have to be accommodated via adaptation, and thereby integrated into a new,  
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56 509 and perhaps dynamic, sense of self. We did not talk to anyone with UC who described their life  
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3 510 as being the same as before the onset of disease. However, for many, the physical burden of  
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6 511 disease will preclude this adaptation and for others there may be a significant period of time  
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8 512 before adaptation is achieved.  
9

10 513  
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12  
13 514 The in-depth participant-focused qualitative research approach used here has allowed us to  
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15  
16 515 gather and analyse rich and detailed accounts of patients' perspectives on living with and  
17  
18 516 adapting to UC. We have talked to a range of patients who have lived with UC for varying  
19  
20  
21 517 periods of time. There are however limitations to our approach. All of the patients interviewed  
22  
23 518 were participating in a pilot trial and as such the range of patients was influenced by the trial  
24  
25  
26 519 eligibility criteria. This meant for example that everybody was in remission at the time of the  
27  
28 520 interview. Those with longstanding mild and controlled disease were less likely to figure in this  
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30  
31 521 research as patients had to have had a relapse within the 12 months preceding recruitment.  
32  
33 522 However, these are potentially the patients most likely to be able to adapt. Additionally this  
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35  
36 523 research is cross-sectional in nature and so we have not been able to observe the temporal  
37  
38 524 components of adaptation over time, although we have interviewed patients who have been  
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40  
41 525 diagnosed with UC between 1 and 22 years. Further research with a broader range of patients  
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43  
44 526 and perhaps with a longitudinal design may provide further insight.  
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46 527  
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48 528 Several patients commented that they had welcomed the opportunity to talk about their views  
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51 529 in-depth to someone outside of the clinical team. A few of them said that they felt that their  
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54 530 clinicians were not always receptive to the broader context that they were able to talk about as  
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56 531 participants in this research. The implications of this for clinical practice need to be explored  
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3 532 further. Naturally, clinicians may focus on the physical and clinical manifestation of disease. As  
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5  
6 533 described here, physical wellbeing is a core component of adaptation and a 'normal life'.  
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8  
9 534 However, physical disease and its impacts are experienced holistically by patients and those  
10  
11 535 around them. The efficacy of medical and surgical management and patients' relationship to  
12  
13 536 this e.g. via adherence, shared decision-making re treatment options, and interactions with  
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15  
16 537 healthcare professionals and services, will be judged by patients within the broader context of  
17  
18 538 adaptation that we have described here. Other authors have recently reflected on the need to  
19  
20  
21 539 identify and address poor adaptation to IBD as a means to impact on quality of life and also  
22  
23 540 potentially the course of disease.<sup>29</sup> The consideration and development of interventions that  
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25  
26 541 facilitate adaptation and self-management in UC may help to reflect the holistic experience and  
27  
28 542 priorities of UC patients.  
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31 543

### 32 33 544 **CONCLUSION**

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36 545 In this study, we have described patients' views on the factors that influence their adaptation  
37  
38 546 to UC and whether they perceived that they are able to regain and maintain a 'normal life'. We  
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40  
41 547 have shown that adaptation to UC is complex and that medication alone is most often  
42  
43 548 insufficient to achieve this. Symptoms, adaptation strategies and outside support all have an  
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45  
46 549 influence on whether patients manage to regain and maintain normality over time. This holistic  
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48 550 view of adaptation to UC will help clinicians and researchers to understand patients' views on  
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51 551 life with the disease and the role of medical and other therapies within this.

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19  
20  
21 561 Alison Moore, Lisa Richardson, and Julie Reddan.

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23 56224  
25  
26 563 **Contributions**

27  
28 564 All authors made a substantial contribution to the manuscript. JM designed and conceived the  
29  
30 565 qualitative research with TP. CM (Research Fellow) conducted the interviews. Data analysis was  
31  
32 566 carried out by CM, JM and LJ, and interpretations checked with all authors. The manuscript was  
33  
34 567 drafted jointly by CM and JM. All authors revised the manuscript for intellectual content. All  
35  
36 568 authors have read and approved the final manuscript.

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41 56942  
43 570 **Patient consent**

44  
45  
46 571 Obtained.

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51 573 **Data sharing statement**

52  
53 574 No additional data are available.

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**FIGURE AND TABLES**

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8 653 Table 1 – Normality types, adapted from Sanderson *et al.* (2011)  
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10 654 Table 2 - Sample characteristics including normality types, adaptation strategies and outside  
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16 656 Table 3 – Adaptation strategies and aims  
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18 657 Figure 1 – Influences on normality in ulcerative colitis  
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Aims of adaptation	Adaptation strategies
<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34</p> <p>Improve physical wellbeing (reduce symptoms and flare ups; prevent triggers of flare ups)</p>	<p>Medication</p> <p>Change diet</p> <p>Probiotic use</p> <p>Complementary therapies (e.g. acupuncture, hypnotherapy)</p> <p>Finding a balance between doing too much and too little (pacing)</p> <p>Exercise</p> <p>Yoga</p> <p>Relaxation classes</p> <p>Smoking</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
<p>35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60</p> <p>Improving psychological wellbeing</p>	<p>Positive and proactive attitude</p> <p>Fighting on / soldiering on in activities (e.g. playing netball, going on holiday)</p> <p>Finding a balance between doing too much and too little (pacing)</p> <p>Mindfulness courses</p> <p>Yoga</p> <p>Relaxation classes</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>

<p>Carry on working</p>	<p>Reducing working hours; selling off part of own business</p> <p>Rearranging working patterns</p> <p>Changing jobs</p> <p>Getting up earlier</p> <p>Finding a balance between doing too much and too little (pacing)</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
<p>Prevent embarrassment</p>	<p>Situational avoidance (not going out; avoiding certain places)</p> <p>Planning (timing, location, duration of activities)</p> <p>Wearing nappies</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>

Table 3 – Adaptation strategies and aims<sup>a</sup>

<sup>a</sup>A number of adaptation methods appear across several categories

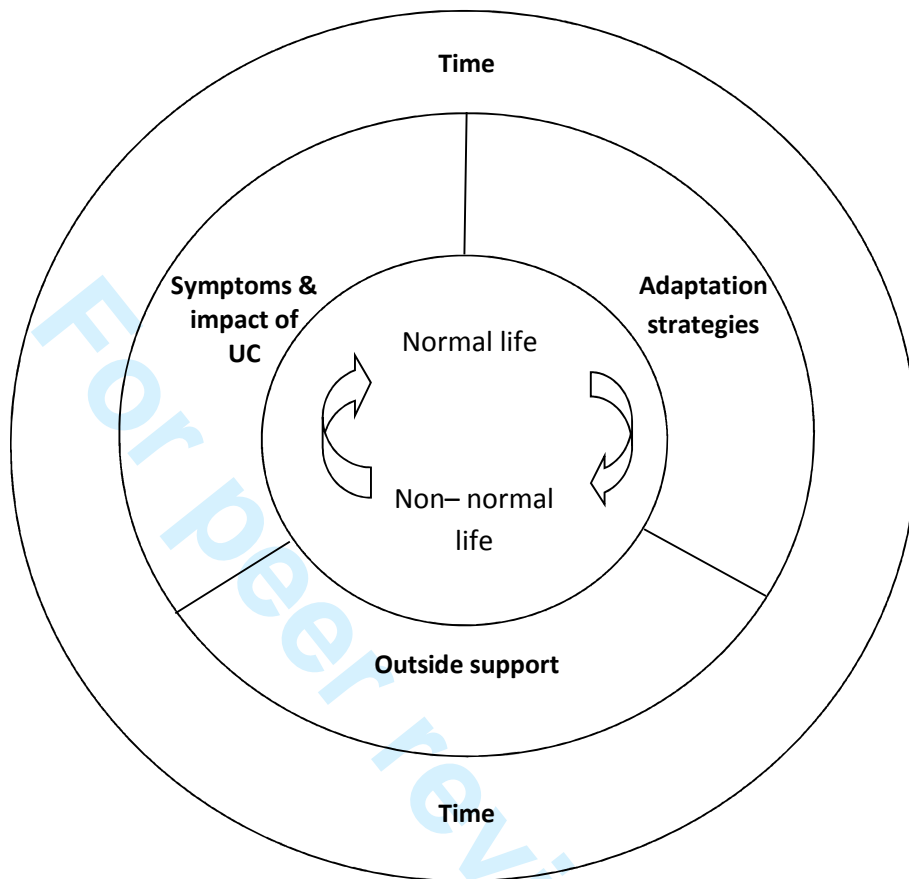
Type / category	Definition and constituent elements
Non-normal life	<ul style="list-style-type: none"> <li>• Some people may find it difficult to accept their condition and attempt to carry on as before, even hiding their condition from others. This may have negative consequences when this is not successful</li> <li>• Symptoms may be devastatingly intrusive and unmanageable for some. It may be difficult or impossible to carry out day-to-day activities, for example, because of symptoms and/or embarrassment, despite acknowledging and trying to adapt to the condition</li> <li>• The condition can threaten peoples' self-identity and associated sense of normality</li> <li>• There may be a feeling of loss of control over the disease and life</li> </ul>
Normal life	<ul style="list-style-type: none"> <li>• For some, medication may be so effective that they can carry on as normal i.e. as before the diagnosis</li> <li>• Other patients may experience mild symptoms with minimal impact on life, daily activities and self-identity, with control facilitated by medication</li> <li>• Some patients with more severe symptoms may reconceptualise normal life by including their condition and its impacts in a life that accommodates the disease. This will include acceptance of the condition and re-orientation of self-identity and thoughts about what constitutes a healthy body</li> </ul>

Table 1 – Normality types - adapted from Sanderson et al. (2011)

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Figure 1 – Influences on normality in ulcerative colitis





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Patient ID	Age	Gender <sup>a</sup>	Ethnicity	Year of diagnosis	Disease severity (Mild, Moderate or Severe) <sup>b</sup>	Medication <sup>c</sup>	Dominant type of normality at interview	Previous period of normality described (non-normal life only) <sup>c</sup>	Adaptation strategies used <sup>c</sup>	Outside support described <sup>c</sup>
1	40	M	White	2004	Moderate/Severe	Y	Non-normal	N	Y	N
2	32	M	White	2013	Mild	Y	Non-normal	N	Y	N
3	37	F	White	2003	Moderate	Y	Non-normal	Y	Y	Y
4	25	F	White	2014	Mild	Y	Non-normal	N	Y	Y
5	57	F	White	2009	Moderate	Y	Non-normal	N	Y	Y
6	33	F	White	2013	Moderate/Severe	Y	Non-normal	N	Y	Y
7	41	M	White	2012	Mild	Y	Non-normal	N	Y	N
8	27	F	Asian British	2009	Moderate	Y	Non-normal	N	Y	Y
9	26	F	White	2011	Mild	Biologics	Normal	N/A	Y	Y
10	57	M	White	2014	Moderate	Y	Non-normal	N	Y	N
11	31	M	Asian British	2002	Mild	Y	Non-normal	Y	Y	N
12	42	M	White	2013	Mild	Y	Normal	N/A	Y	N
13	27	M	White	2013	Mild	Y	Normal	N/A	Y	Y
14	21	F	White	2014	Moderate	Biologics	Non-normal	N	Y	N

15	40	F	White	1995	Moderate	Y	Normal	N/A	Y	Y
16	22	M	White	2014	Moderate	Y	Non-normal	N	Y	Y
17	36	M	White	2006	Mild	Y	Normal	N/A	Y	N
18	54	M	White	2014	Mild	Y	Normal	N/A	Y	N
19	42	F	White	2003	Moderate	Y	Normal	N/A	Y	Y
20	18	M	Asian British	2014	Mild/Moderate	Y	Non-normal	N	Y (medication only)	Y
21	44	M	White	2012	Moderate/Severe	Y	Non-normal	N	Y	Y
22	50	M	White	1993	Mild	Y	Normal	N/A	Y	N
23	30	F	White	2014	Mild	Y	Normal	N/A	Y (medication only)	Y
24	43	M	White	2003	Mild	N	Normal	N/A	Y	Y
25	41	M	Asian British	2013	Mild	Y	Non-normal	N	Y	N
26	51	M	White	2004	Moderate	Y	Normal	N/A	Y	Y
27	37	F	White	2011	Mild/Moderate	Biologics	Normal	N/A	Y	Y
28	40	F	White	2013	Moderate	Y	Non-normal	N	Y	N

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**Table 2 - Sample characteristics including normality types, adaptation strategies and outside support**

<sup>a</sup>M = male, F = female

<sup>b</sup>Disease severity was categorised based on patients' descriptions of their symptoms and through analysis of this and descriptions of the impacts of UC that patients provided e.g. the amount of time patients took off work, and the number of flare ups patients described.

<sup>c</sup>Y =Yes, N = No

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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## Adapting to ulcerative colitis to try to live a 'normal' life: a qualitative study of patients' experiences in the Midlands region of England

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017544.R1
Article Type:	Research
Date Submitted by the Author:	21-Jun-2017
Complete List of Authors:	McMullan, Christel; University of Birmingham, Institute of Applied Health Research Pinkney, Tom; University of Birmingham, Academic Department of Surgery Jones, Laura; University of Birmingham, Institute of Applied Health Research Magill, Laura ; University of Birmingham, Birmingham Clinical Trials Unit Nepogodiev, Dmitri; University of Birmingham, Academic Department of Surgery Pathmakanthan, Shri; University Hospitals Birmingham NHS Foundation Trust, Department of Gastroenterology Cooney, Rachel; University Hospitals Birmingham NHS Foundation Trust, Department of Gastroenterology Mathers, Jonathan; University of Birmingham, Institute of Applied Health Research
<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Gastroenterology and hepatology, Qualitative research
Keywords:	QUALITATIVE RESEARCH, ulcerative colitis, adaptation, normality, Gastroenterology < INTERNAL MEDICINE

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Manuscripts

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3 1 **Adapting to ulcerative colitis to try to live a 'normal' life: a qualitative study of patients'**  
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6 2 **experiences in the Midlands region of England**  
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4 **Authors**5 Christel McMullan, PhD<sup>a</sup>; Thomas D Pinkney, MMedED<sup>b</sup>; Laura L Jones, PhD<sup>a</sup>; Laura Magill, PhD<sup>c</sup>;6 Dmitri Nepogodiev, MBChB<sup>b</sup>; Shri Pathmakanthan, DM<sup>d</sup>; Rachel Cooney, PhD<sup>d</sup>; Jonathan M7 Mathers, PhD<sup>a</sup>

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3 23 **Keywords:** qualitative studies, ulcerative colitis, adaptation, normality  
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56 28 **ABSTRACT**  
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910 30 **Objective**  
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13 31 To provide a framework that is able to categorise whether patients are able to adapt to and  
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16 32 lead a 'normal' life with ulcerative colitis (UC) and to detail the factors that influence this.  
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19 3320 34 **Design**  
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23 35 Qualitative research study using in-depth semi-structured interviews.  
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28 37 **Setting**  
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31 38 Four clinical sites in the West and East Midlands regions of England.  
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36 40 **Participants**  
3738 41 28 adult patients diagnosed with UC for between 1 and 22 years.  
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43 43 **Results**  
4445  
46 44 Medication was rarely sufficient for patients to adapt to UC and live as 'normal' a life as  
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49 45 possible. Virtually all patients tested and adopted non-medical adaptation methods to improve  
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54 47 embarrassment. In addition, some patients benefited from outside support, providing them  
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56 48 with practical, emotional, and/or financial help. In conjunction with adaptation strategies and  
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3 49 the time to adapt, this meant that some patients with severe clinical disease were able to  
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6 50 maintain a sense of normality in life. Patients reported that clinicians were not always  
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9 51 receptive to discussion of the broader context of life with UC.

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### 13 **Conclusions**

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16 54 Patients' experience of UC and their ability to adapt in order to maintain a sense of normality in  
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19 55 life is a complex interplay of symptoms, adaptation strategies and outside support. Over time  
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22 56 patients test out a variety of non-medical adaptation strategies. Awareness of this may help  
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25 57 clinicians and researchers to understand patients' views on the role of medical and other  
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28 58 therapies. Further research around the utility of this framework in clinical practice and  
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31 59 research is now required.

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### 34 **Strengths and limitations of this study**

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36 62 • This study is an in-depth participant-focused qualitative study providing rich and detailed  
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39 63 accounts of patients' experiences of living with and adapting to UC.
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41 64 • This is the first detailed analysis that has attempted to categorise whether patients are able  
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44 65 to adapt to and lead a 'normal' life with UC, and also to detail the factors that influence  
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47 66 this.
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49 67 • The semi-structured interviews provided patients the opportunity to talk about their  
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52 68 experience to someone outside of their clinical team.
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54 69 • The research is cross-sectional in nature, limiting the potential to observe the temporal  
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57 70 components of adaptation over time.
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3 71 • The patients interviewed were participating in a pilot trial, which means that the range of  
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6 72 patients was influenced by the trial eligibility criteria.  
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11 **Funding**

12  
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14  
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18 77  
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21 **Competing interests**

22  
23 79 The authors confirm that they have no conflict of interest to disclose.  
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6 83**INTRODUCTION**

84 Ulcerative colitis (UC) is a form of chronic inflammatory bowel disease (IBD) which affects the  
85 large bowel. Over 145,000 people in the UK<sup>1</sup> and 900,000 in the USA<sup>2</sup> are living with UC. The  
86 condition is most prevalent in Northern Europe and North America, although the number of  
87 people affected by UC is increasing recently in developing countries.<sup>3</sup> There is also an  
88 increasing incidence of UC among younger patients.<sup>4</sup> Around 40% of patients will experience a  
89 relapse annually, with between 20% and 30% requiring total colectomy in their lifetime.<sup>5,6</sup>  
90 Reducing relapse rates and disease progression is a priority for patients.<sup>7</sup> Ulcerative colitis has  
91 been shown to have a significant negative impact on Health-Related Quality of Life (HRQoL).<sup>8</sup>  
92 Whilst many patients' lives are severely disrupted as, for example, the disease affects their  
93 ability to work as well as their social and family life,<sup>8-11</sup> these impacts are not always directly  
94 correlated, from a clinical perspective, with disease activity and severity of symptoms.<sup>12</sup>  
95 Patients with mild clinical disease can experience significant impacts on HRQoL and  
96 psychological morbidity, whilst some with apparently severe disease activity seem to 'cope'  
97 relatively well.

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99 Commentators have argued that often the focus of the medical management of IBD is too much  
100 on acute episodes, not necessarily reflecting the chronicity of IBD and therefore the overall  
101 patient experience of disease over time.<sup>13</sup> Understanding more about living with IBD can help  
102 to highlight the role that medical and surgical management plays. The patient perspective on

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3 103 living with UC may sometimes be difficult for clinicians to interpret as they may underestimate  
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6 104 or overlook the overall effects of disease on patients' lives.<sup>8</sup>

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11 106 Qualitative research is well placed to describe and understand patients' views on disease and  
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13 107 treatment.<sup>14</sup> Within IBD and UC there is a small but informative body of qualitative research  
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16 108 relevant to these issues and work to date has described patients' perspectives on the impact of  
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18 109 IBD; of the physical symptoms, and broader issues, for example, on work, lifestyle, daily  
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21 110 activities, social life, and psychological well-being.<sup>8-11,15-20</sup> Research has suggested that patients  
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23 111 are engaged in a 'fight' for some sort of health-related normality and that achieving a 'new  
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26 112 normal' is their ultimate goal.<sup>15</sup> Trying to live as 'normal' a life as possible is something that  
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28 113 patients reflect upon when they talk about life with IBD.<sup>12</sup> This body of research describes  
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31 114 patients' views on how their lives are affected by IBD and shows that adaptation (i.e. a desire  
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33 115 for normality) is an overriding concern. However, to date nobody has provided a clear  
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36 116 framework to help understand normality and adaptation in UC.

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41 118 The aim of this paper is therefore twofold; (1) to provide a framework that is able to categorise  
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43 119 whether patients are able to adapt to and lead a 'normal' life with UC and (2) to detail the  
44  
45  
46 120 factors that influence this.

47  
48 121

## 51 122 **METHODS**

### 53 123 **Setting and study design**

1  
2  
3 124 Participants were recruited from four hospitals in the West and East Midland regions of England  
4  
5  
6 125 and were taking part in the National Institute for Health Research (NIHR) Research for Patient  
7  
8 126 Benefit-funded ACCURE-UK trial.<sup>21</sup> This randomised external pilot trial was exploring the  
9  
10  
11 127 feasibility of a multi-centre randomised controlled trial (RCT) of therapeutic appendicectomy  
12  
13 128 for the treatment of UC (intervention arm) in addition to standardised medical therapy (control  
14  
15  
16 129 arm). The trial included integrated qualitative research, the main aim of which was to  
17  
18 130 investigate the acceptability of the trial and understand this within the context of patients'  
19  
20  
21 131 everyday lives with UC.

22  
23 132 The theoretical underpinnings of our approach most closely align with interpretive description.  
24  
25  
26 133 Originally described in nursing and drawing on methods from established qualitative  
27  
28 134 methodologies this approach has a heavy emphasis on understanding and informing clinical  
29  
30  
31 135 practice.<sup>22,23</sup> The research methods we describe (e.g. for interviews – broad purposive  
32  
33 136 sampling, iterative in-depth data collection and inductive analysis without a priori theoretical  
34  
35  
36 137 tools) are concordant with a generic interpretive approach to addressing our research aims.  
37  
38  
39 138

### 40 41 139 **Sampling and recruitment**

42  
43 140 We recruited a diverse sample (age, gender, time since diagnosis) of patients from both arms of  
44  
45  
46 141 the pilot RCT. Clinical staff initially discussed the qualitative research with patients. With  
47  
48  
49 142 consent, the contact details of patients expressing an interest were passed to the researcher  
50  
51 143 conducting the interviews (CM), who then took informed consent prior to interview.  
52

53  
54 144

### 55 56 145 **Data collection**

1  
2  
3 146 Semi-structured one-to-one interviews were conducted by CM between randomisation and  
4  
5  
6 147 surgery for those allocated to intervention arm, and shortly after randomisation for those in the  
7  
8  
9 148 control arm. CM is a non-clinical trained qualitative researcher independent from participants'  
10  
11 149 clinical care and the day-to-day trial management. This was clearly communicated to  
12  
13 150 participants. Participants were asked to select a convenient time and place for interview. Most  
14  
15  
16 151 chose to be interviewed at home, although a small number of interviews were conducted on  
17  
18  
19 152 hospital or university premises, or by telephone.  
20

21 153  
22  
23 154 The interview schedule was informed by the existing literature and consultation with the wider  
24  
25  
26 155 research team. It included discussion of patients' views and experience of life with UC since  
27  
28  
29 156 initial diagnosis: their symptoms, their flare ups and their impacts, their medical treatment, and  
30  
31 157 their perspectives on adaptation to UC. In addition, a section of the interview focused on  
32  
33  
34 158 participants' perspectives on the RCT and trial processes (data not reported here). Interviews  
35  
36 159 were conducted in a participant-focused open-ended manner. After initial piloting, data  
37  
38  
39 160 collection and analysis took place iteratively. This continued until the research team judged  
40  
41 161 that the data and sample had sufficient depth and breadth to address initial research  
42  
43  
44 162 questions.<sup>24</sup> Field notes were kept after the interviews to record factors that might have  
45  
46 163 influenced the conduct and the analysis of the interviews.  
47

48 164

#### 51 165 **Data analysis**

52  
53 166 All interviews were audio-recorded and transcribed verbatim by a specialist external  
54  
55  
56 167 transcription company. Data were analysed thematically and managed using Computer-Aided  
57  
58  
59  
60

1  
2  
3 168 Qualitative Data Analysis Software (CAQDAS), NVivo10. The analysis was informed by the  
4  
5  
6 169 Framework analytical approach.<sup>25</sup> Firstly, interview transcripts were reviewed several times and  
7  
8  
9 170 open coding was undertaken. These codes were then reviewed and categorised and the  
10  
11 171 dataset indexed. Categories were refined into overarching themes from descriptive accounts of  
12  
13 172 the data. Final analysis and explanation was facilitated by use of a typology and associative  
14  
15  
16 173 analysis using charting. The analytic typology is described in more detail below. A sample of  
17  
18 174 interviews were coded by an independent researcher during initial coding. The research team  
19  
20  
21 175 ensure not only that code saturation was reached but also that we had a deep and rich  
22  
23 176 understanding of that the themes derived during analysis were about.<sup>26</sup> The final analysis and  
24  
25  
26 177 interpretation were discussed amongst the research team, and with one patient who took part  
27  
28 178 in the interviews.

30  
31 179

### 32 33 180 **Analytic typology**

34  
35  
36 181 During analysis we have applied a typology devised from qualitative data gathered with  
37  
38 182 patients with rheumatoid arthritis, another chronic inflammatory disease of relapsing remitting  
39  
40  
41 183 nature.<sup>27</sup> A typology is a classification system that consists of categories that describe different  
42  
43 184 types of a phenomenon of interest; here adaptation to life with UC and the ability to attain a  
44  
45  
46 185 new sense of normality. Typologies are sometimes used to categorise observations in  
47  
48 186 qualitative data.<sup>28</sup>

49  
50  
51 187 In addressing our first research aim we have categorised participants into two types (see Table  
52  
53 188 1 & Table 2), one of broadly positive experience and adaptation to UC ('the normal life') and  
54  
55  
56 189 one of negative experience and non-adaptation ('the non-normal life'). This typology  
57  
58  
59  
60



1  
2  
3 190 encompasses patients' reactions to their illness, their attempts to adapt to it, and success or  
4  
5  
6 191 failure in this. Of note, these are not static categorisations; patients may move between them,  
7  
8  
9 192 over time, and as a consequence of changing circumstances. We have used the accounts given  
10  
11 193 by participants during the interviews to assign them to these two broad categories, at the time  
12  
13  
14 194 of the interview, and at time points since diagnosis.  
15  
16 195

Type / category	Definition and constituent elements
Non-normal life	<ul style="list-style-type: none"> <li>• Some people may find it difficult to accept their condition and attempt to carry on as before, even hiding their condition from others. This may have negative consequences when this is not successful</li> <li>• Symptoms may be devastatingly intrusive and unmanageable for some. It may be difficult or impossible to carry out day-to-day activities, for example, because of symptoms and/or embarrassment, despite acknowledging and trying to adapt to the condition</li> <li>• The condition can threaten peoples' self-identity and associated sense of normality</li> <li>• There may be a feeling of loss of control over the disease and life</li> </ul>
	<ul style="list-style-type: none"> <li>• For some, medication may be so effective that they can carry on as normal i.e. as before the diagnosis</li> </ul>

Normal life	<ul style="list-style-type: none"> <li>• Other patients may experience mild symptoms with minimal impact on life, daily activities and self-identity, with control facilitated by medication</li> <li>• Some patients with more severe symptoms may reconceptualise normal life by including their condition and its impacts in a life that accommodates the disease. This will include acceptance of the condition and re-orientation of self-identity and thoughts about what constitutes a healthy body</li> </ul>
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196 *Table 1 – Normality types - adapted from Sanderson et al. (2011)*

197

## 198 **ETHICAL CONSIDERATIONS**

199 Ethical approval for the ACCURE-UK trial was granted from the North East Tyne and Wear South  
 200 Research Ethics Committee, REC number 14/NE/1143.

201

## 202 **RESULTS**

203 The following analysis is based on data from interviews with 28 patients (Table 2), which lasted  
 204 between 22 and 58 minutes; 16 women and 12 men aged between 18 and 57; 24 of white and  
 205 4 of Asian ethnic origin; diagnosed with UC between 1 and 22 years. All were in remission at  
 206 the time of interview but had experienced a disease relapse within the preceding 12 months  
 207 (RCT eligibility criteria). All but one were on medical therapy, with three having taken biologic  
 208 therapies, such as infliximab and adalimumab. One patient had decided to discontinue all  
 209 medical therapy due to side effects. None had undergone any colonic surgery previously. There  
 210 was no withdrawal.

211

Patient ID	Age	Year of diagnosis	Marital status	Employment status	Disease severity (Mild, Moderate or Severe) <sup>a</sup>	Medication <sup>b</sup>	Dominant type of normality at interview	Previous period of normality described (non-normal life only) <sup>b</sup>	Adaptation strategies used <sup>b</sup>	Outside support described <sup>b</sup>
1	31-40	2004	Married	Self-employed	Moderate/Severe	Y	Non-normal	N	Y	N
2	31-40	2013	Married	Employed	Mild	Y	Non-normal	N	Y	N
3	31-40	2003	Married	Employed	Moderate	Y	Non-normal	Y	Y	Y
4	21-30	2014	Cohabiting	Employed	Mild	Y	Non-normal	N	Y	Y
5	51-60	2009	Married	Not employed	Moderate	Y	Non-normal	N	Y	Y
6	31-40	2013	Married	Employed	Moderate/Severe	Y	Non-normal	N	Y	Y
7	41-50	2012	Single	Self-employed	Mild	Y	Non-normal	N	Y	N
8	21-30	2009	Single	Employed	Moderate	Y	Non-normal	N	Y	Y
9	21-30	2011	Single	Employed	Mild	Biologics	Normal	N/A	Y	Y

1											
2											
3											
4	<b>10</b>	51-60	2014	Divorced	Self-employed	Moderate	Y	Non-normal	N	Y	N
5											
6	<b>11</b>	31-40	2002	Single	Employed	Mild	Y	Non-normal	Y	Y	N
7											
8											
9	<b>12</b>	41-50	2013	Divorced	Self-employed	Mild	Y	Normal	N/A	Y	N
10											
11											
12	<b>13</b>	21-30	2013	Single	Employed	Mild	Y	Normal	N/A	Y	Y
13											
14											
15	<b>14</b>	21-30	2014	Single	Employed	Moderate	Biologics	Non-normal	N	Y	N
16											
17											
18	<b>15</b>	31-40	1995	Single	Employed	Moderate	Y	Normal	N/A	Y	Y
19											
20											
21	<b>16</b>	21-30	2014	Single	Employed	Moderate	Y	Non-normal	N	Y	Y
22											
23											
24	<b>17</b>	31-40	2006	Single	Employed	Mild	Y	Normal	N/A	Y	N
25											
26											
27	<b>18</b>	51-60	2014	Separated	Not known	Mild	Y	Normal	N/A	Y	N
28											
29											
30	<b>19</b>	41-50	2003	Married	Employed	Moderate	Y	Normal	N/A	Y	Y
31											
32											
33	<b>20</b>	<20	2014	Single	Unemployed	Mild/Moderate	Y	Non-normal	N	Y	Y
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35											
36										(medication	
37										only)	
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21	41-50	2012	Married	Self-employed	Moderate/Severe	Y	Non-normal	N	Y	Y
22	41-50	1993	Married	Employed	Mild	Y	Normal	N/A	Y	N
23	21-30	2014	Cohabiting	Employed	Mild	Y	Normal	N/A	Y (medication only)	Y
24	41-50	2003	Married	Employed	Mild	N	Normal	N/A	Y	Y
25	41-40	2013	Married	Employed	Mild	Y	Non-normal	N	Y	N
26	51-60	2004	Married	Employed	Moderate	Y	Normal	N/A	Y	Y
27	31-40	2011	Married	Employed	Mild/Moderate	Biologics	Normal	N/A	Y	Y
28	31-40	2013	Married	Employed	Moderate	Y	Non-normal	N	Y	N

212 **Table 2 - Sample characteristics including normality types, adaptation strategies and outside support**

213 <sup>a</sup>Disease severity was categorised based on patients' descriptions of their symptoms and through analysis of this and descriptions of the impacts of UC that  
 214 patients provided e.g. the amount of time patients took off work, and the number of flare ups patients described.

215 <sup>b</sup>Y =Yes, N = No

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3 2164  
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6 217 Findings are presented as follows:

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- 8 218 • the normality types experienced and described by our participants
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- 9
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- 10 219 • their adaptation strategies and intended purpose
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- 11
- 
- 12 220 • the outside support to adaptation and;
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- 13
- 
- 14 221 • how these factors interact with symptoms to influence the ability of a patient with UC to
- 
- 15
- 
- 16 222 lead a normal life
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23  
24 224 **Participants' descriptions of normal and non-normal life since diagnosis**25  
26 225 Our analysis of patients' accounts suggests that at the point of interview, 12 of the 28  
27  
28 226 participants in this sample could be categorised as experiencing some form of normal life with  
29  
30 227 UC. There was no clear relationship between the length of time since diagnosis and the type of  
31  
32 228 normality they were experiencing at the time of the interview. At diagnosis, all participants had  
33  
34 229 described a period of non-normal life with significant disruption due to disease activity and  
35  
36 230 symptoms. Some also talked about a need to understand and acknowledge the significance of  
37  
38 231 the diagnosis itself. Participants suffered from intrusive symptoms (stomach cramps, bleeding,  
39  
40 232 more frequent bowel movements) and in many cases it took several months to receive a  
41  
42 233 definitive diagnosis and treatment, with several patients ending up being admitted to hospital.  
43  
44 234 As a result, they had to take time off work and were not able to carry on with their daily  
45  
46 235 activities:  
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51  
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54 236

1  
2  
3 237 *“Diagnosed in October. We were actually away in Spain when I had the flare up, and I*  
4  
5  
6 238 *was in hospital in Spain for a week, and they did all the tests there, then when I got back*  
7  
8  
9 239 *to England they did it all again in October. I was due to go in for the camera, and when I*  
10  
11 240 *got there they said that I’d got so weak that they wouldn’t be able to do it, but they kept*  
12  
13 241 *me in, and obviously I was in hospital then for three weeks, or nearly four weeks I believe*  
14  
15  
16 242 *it was at the time” (Patient 18)*  
17

18 243  
19  
20  
21 244 Following an initial period of disruption and non-normal life around the time of diagnosis  
22  
23 245 participants’ accounts vary, with some seemingly not having attained or regained any sense of a  
24  
25  
26 246 normal life. Others had managed to do so, some temporarily. Only three patients described a  
27  
28 247 period where they felt that they had been relatively unaffected as their symptoms were largely  
29  
30  
31 248 controlled by medication, such that they were able to carry on life without much perceived  
32  
33 249 impact. For example, one male participant who was diagnosed in 2002 talked about not having  
34  
35  
36 250 a flare up whilst managing UC for the first five years with medication. None of the participants  
37  
38 251 indicated that medication had dealt with all of their symptoms to the extent that life was the  
39  
40  
41 252 same as before the onset of disease.  
42

43 253  
44  
45

#### 46 254 **Participants’ descriptions of adaptation strategies and their intended purpose**

47

48 255 During the interviews all participants described attempts to adapt to their condition, and all but  
49  
50  
51 256 two participants actively tested or adopted approaches that were additional to medical  
52  
53  
54 257 therapies. We have categorised the adaptation strategies described according to their  
55  
56 258 intended purpose. Most commonly participants aimed to achieve four things (Table 3):  
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16 264  
17

- To improve physical wellbeing
- To improve psychological wellbeing
- To carry on working
- To prevent embarrassment

Aims of adaptation	Adaptation strategies
Improve physical wellbeing (reduce symptoms and flare ups; prevent triggers of flare ups)	Medication  Change diet  Probiotic use  Complementary therapies (e.g. acupuncture, hypnotherapy)  Finding a balance between doing too much and too little (pacing)  Exercise  Yoga  Relaxation classes  Smoking  Personal research (inc. forums, Crohn’s and



	Colitis UK, social media)
Improving psychological wellbeing	<p>Positive and proactive attitude</p> <p>Fighting on / soldiering on in activities (e.g. playing netball, going on holiday)</p> <p>Finding a balance between doing too much and too little (pacing)</p> <p>Mindfulness courses</p> <p>Yoga</p> <p>Relaxation classes</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
Carry on working	<p>Reducing working hours; selling off part of own business</p> <p>Rearranging working patterns</p> <p>Changing jobs</p> <p>Getting up earlier</p>

	<p>Finding a balance between doing too much and too little (pacing)</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
Prevent embarrassment	<p>Situational avoidance (not going out; avoiding certain places)</p> <p>Planning (timing, location, duration of activities)</p> <p>Wearing nappies</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>

265 *Table 3 – Adaptation strategies and aims<sup>a</sup>*

266 <sup>a</sup>A number of adaptation methods appear across several categories

267

268 Improve physical wellbeing

269 This category describes participants' strategies to reduce physical symptoms and the frequency  
 270 of UC flare ups, and also to do so by addressing perceived triggers of flare ups. The physical  
 271 symptoms were a very important part of the great majority of patients' accounts, as they made  
 272 them extremely fatigued:

273

1  
2  
3 274 *“Just draining, not tired, not sleepy, just drained. [Name] knows what I’m like, by the*  
4  
5  
6 275 *time I’ve been five times and I’ve just got no energy, just no energy to do anything, and I*  
7  
8 276 *just the best thing is just to give into it. I say to [name], you’re going to have to count me*  
9  
10 277 *out for the rest of the day, and just give into it” (Patient 21)*

13  
14 278

16 279 The most common adaptation approach in this category was medication, with all but one  
17  
18 280 participant taking regular medication to improve physical wellbeing. The one participant, who  
19  
20  
21 281 had ceased taking medication due to side effects, reported that smoking helped to reduce  
22  
23 282 symptoms. During the interviews it was clear that there were varied perspectives on whether  
24  
25  
26 283 medication was ‘working’. Some reported that medication was effective and others that it was  
27  
28 284 not. Some participants were unsure as to how much it helped:

30  
31 285

33 286 *“I don’t notice any effect with the anti-inflammatories (...) It generally doesn’t keep it*  
34  
35  
36 287 *[UC] away, because like I say I can be fully recovered, go nine/ten months of the year*  
37  
38 288 *whilst taking anti-inflammatories every day, and still go into a flare up. But whether if I*  
39  
40  
41 289 *didn’t take them I don’t know if I’d go into a flare up quicker. So I don’t know” (Patient*

42  
43 290 1)44  
45  
46 291

48 292 Another common adaptation approach to improve physical wellbeing was to change diet. As  
49  
50  
51 293 with other adaptation approaches, this was often a trial and error strategy with the aim to  
52  
53  
54 294 establish which foods tended to worsen symptoms or trigger flares. Some people reported

1  
2  
3 295 keeping a food diary for several weeks or months to identify patterns in their food intake and  
4  
5  
6 296 symptoms:

7  
8 297  
9  
10 298 *“When I came out of hospital for about a month I kept a list of all the food I’d eaten*  
11  
12 *every day and what I’d drank, so that if I went into a flare up I could look back and say*  
13 299 *maybe it was that, so I’ll try it one more time and if it happens again I’ll not eat or drink*  
14  
15 300 *that again”* (Patient 10)  
16  
17  
18 301  
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21 302

22  
23 303 Other adaptation strategies in this category include the use of complementary therapies (e.g.  
24  
25 304 acupuncture or hypnotherapy), exercise, yoga, relaxation courses to avoid triggers (stress), and  
26  
27 305 the pacing of activities to find a balance between symptoms and the ability to do things.  
28  
29  
30  
31 306

32  
33 307 Improve psychological wellbeing

34  
35  
36 308 When discussing issues pertaining to psychological wellbeing several participants stated that  
37  
38 309 they have a positive and proactive outlook on life with UC. We believe that this signals  
39  
40 310 acceptance that the disease was not going to go away, and describes an associated attitude and  
41  
42 311 approach to living with it. This was sometimes evident in discussions about the need to ‘soldier  
43  
44 312 on’ and maintain some or all of the activities that participants pursued prior to diagnosis, such  
45  
46 313 as playing sports, going out, and going on holiday. Often, similar to other adaptations, this  
47  
48 314 would involve a process of testing the boundaries of what was possible and finding a balance  
49  
50 315 between the desire to keep going and the potential negative (e.g. physical) consequences of  
51  
52 316 doing too much. For example, Patient 19, a 42 year old woman first diagnosed in 2003  
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1  
2  
3 317 described how, over the years, she adapted her activities to have more control of her condition,  
4  
5  
6 318 but was keen not to be a 'victim', which she likened to being 'too depressive':  
7

8 319  
9  
10  
11 320 *"I just refuse to give up and not do anything, and I know that the exercise is good for me.*  
12  
13 321 *But equally I know that doing too much exercise is bad for me, because it will make me ill*  
14  
15 322 *and run down (...) refusing to not do anything and be a victim and just sit at home doing*  
16  
17 323 *nothing, because that's just too depressing to even think about isn't it?" (Patient 19)*  
18  
19

20 324  
21  
22  
23 325 Specific activities that were adopted by participants in an attempt to improve psychological  
24  
25  
26 326 wellbeing included attending mindfulness and relaxation courses, and also yoga.  
27

28 327  
29  
30  
31 328 Carry on working  
32  
33 329 Being able to maintain a working life was expressed as a key concern by the majority of our  
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35  
36 330 participants. The main strategy in order to carry on working was reducing working hours,  
37  
38 331 because of fatigue (one of the most commonly reported physical symptoms), a lack of  
39  
40 332 concentration and the need to constantly be near toilets. Spending less time in work meant  
41  
42 333 that participants had more time for themselves to rest at home:  
43  
44  
45

46 334  
47  
48 335 *"There's certain things I can't do at work, like I don't do playground duty, because that*  
49  
50 336 *way I get an extra break, I don't teach PE, it just wears me out really, it is quite a physical*  
51  
52 337 *job. I've had to reduce my days as well, I did work three days a week before I was*  
53  
54 338 *diagnosed, and now I only work two"* (Patient 6)  
55  
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3 339  
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6 340 Participants who reduced their working hours found themselves to be more efficient at work.  
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8  
9 341 However, this had a financial impact, placing burden on participants and their families.  
10  
11 342 Other strategies to maintain working included rearranging working patterns (e.g. working only  
12  
13 343 in the afternoon as symptoms were worse in the morning; spreading working hours throughout  
14  
15  
16 344 the week), changing jobs to something less demanding, and getting up earlier in the morning to  
17  
18 345 have more time to deal with the symptoms and be ready in time for work.  
19  
20  
21 346

22  
23 347 Prevent embarrassment  
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25  
26 348 Avoiding and preventing the embarrassment potentially caused by UC was a key theme in the  
27  
28 349 data. This very often restricted participants in their daily life, for example, with the fear of  
29  
30  
31 350 being embarrassed by not being able to find toilets when needed:  
32

33 351  
34  
35  
36 352 *"I don't go out as much as I did before, and when I go out I'm very nervous, first thing I*  
37  
38 353 *do a check where is the nearest toilet even if I don't need it, and some days if my friends*  
39  
40  
41 354 *want to go out or do something I might be too fatigued"* (Patient 4)  
42

43 355  
44  
45  
46 356 One strategy employed to prevent embarrassment was situational avoidance with some  
47  
48 357 participants reporting not going out or not going to places where toilets are not readily  
49  
50  
51 358 available. Whilst such avoidance may be perceived as being effective in preventing  
52  
53 359 embarrassment, in turn it could result in feelings of isolation:  
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1  
2  
3 361 *“Well because I’ve been having so many flare ups and been unwell a lot I don’t have so*  
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5  
6 362 *much of a social life now, and every time I try and plan things in I end up being ill a lot*  
7  
8  
9 363 *and having to cancel all the time, so I stopped making forward plans now to be honest,*  
10  
11 364 *because if there are things a few months away I just say to friends that I have to let you*  
12  
13 365 *know at the time, because I never know what my health is going to be like. So it has had*  
14  
15  
16 366 *quite an impact socially. It can be a bit isolating as well, that’s a bit difficult” (Patient 8)*  
17

18 367  
19  
20  
21 368 Other participants discussed having to carefully plan, such as for nights out, around the location  
22  
23 369 of the toilets, to limit the frequency of their social outings, or to try to plan them during  
24  
25  
26 370 remission periods. Finally, one patient reported being able to go out because he was wearing  
27  
28 371 nappies, which meant he was not as restricted by the location of toilets.  
29

30  
31 372  
32  
33 373 Personal research, including participation in disease-specific internet forums and social media  
34  
35  
36 374 was described as contributing to each of the aims associated with adaptation strategies that  
37  
38 375 were tested by patients:  
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41 376  
42  
43 377 *“It’s just a Facebook group of everybody who has got Crohn’s and colitis really, it’s a*  
44  
45  
46 378 *group where you could obviously speak to other people about your condition. There’s*  
47  
48  
49 379 *quite a lot of support on there, and it has been mentioned, and so there’s obviously*  
50  
51 380 *people already know already. There seems to be a lot of support for anything,*  
52  
53  
54 381 *awareness of disease, and look at ways of improving the condition” (Patient 3)*  
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3 383 **Outside support to adaptation**  
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5  
6 384 Some patients spoke about the influence of outside support in enabling life and adaptation to  
7  
8 385 UC. Such support was not necessarily asked for or actively sought by participants but  
9  
10 386 nevertheless helped them live and manage UC on a day-to-day basis. They provided an  
11  
12  
13 387 invaluable source of social support for several participants.  
14

15 388

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17  
18 389 The main support evident in the data were:  
19

- 20  
21 390 • Help from parents/close family members (practical, emotional, and financial)  
22  
23 391 • Help from a partner and/or children (practical and emotional)  
24  
25  
26 392 • Help from friends (practical and emotional)  
27  
28 393 • Help from employer/workplace (practical)  
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31 394

32  
33 395 Support from parents and other close family members included moving closer to participants or  
34  
35  
36 396 having them live with them in order to help with day-to-day tasks e.g. the school run,  
37  
38 397 household chores, and give them financial help:  
39

40  
41 398

42  
43 399 *“My parents have moved house to be nearer (...) But they rushed the move because I was*  
44  
45  
46 400 *poorly, they actually moved while I was in hospital, because while I was in hospital they*  
47  
48  
49 401 *were staying here for half the week to have my boys, because when I was in hospital*  
50  
51 402 *both my boys were preschool age, they were two and four, so obviously someone had to*  
52  
53  
54 403 *have them.” (Patient 6)*  
55

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3 405 Participants also often discussed the practical and emotional support provided by their partners  
4  
5  
6 406 and children:

7  
8 407  
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10  
11 408 *“Luckily my daughter is quite mature for her age, because she’s only 11, but she does*  
12  
13 409 *understand, and she’s quite good, and she will help me, and if I need help she is always*  
14  
15 410 *there, and make me a cup of tea and little things like that. So yes quite lucky in that*  
16  
17 411 *respect.” (Patient 15)*  
18  
19

20  
21 412  
22  
23 413 Finally, work managers and the workplace often offered practical support to patients, mainly by  
24  
25 414 providing flexible working hours, helping them to attend hospital appointments or deal with the  
26  
27 415 impact of symptoms:  
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31 416  
32  
33 417 *“Work have been pretty good, been really good with allowing me time off for*  
34  
35 418 *appointments and things.” (Patient 23)*  
36  
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38 419  
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40  
41 420 One patient described how his workplace had recognised UC as a disability, and that this was  
42  
43 421 invaluable in providing the means to accommodate the impacts of the disease e.g. by taking  
44  
45 422 time off work for hospital appointments or because of symptoms.  
46  
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48 423  
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51 424 **How symptoms, adaptation strategies and outside support interact to influence adaptation**  
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53 425 **and the ability to live a normal life with UC**  
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3 426 Whether patients are able to maintain or regain a sense of a normal life with UC appears to be  
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5  
6 427 a complex interplay between disease activity and symptoms, the impacts of these, attempts to  
7  
8 428 adapt, and outside support (Figure 1). Those patients who, overall, describe and judge their  
9  
10 429 disease activity to be mild were also more likely to indicate that they were able to regain a  
11  
12 430 sense of normality. Most, but not all of these patients, thought that their medication was  
13  
14 431 successful in helping them control symptoms and impacts. All but one had adopted some  
15  
16 432 adaptation strategies and half described the positive influence of outside support. However,  
17  
18 433 several patients who described mild disease did not convey a sense of a normal life. Most of  
19  
20 434 these had been diagnosed relatively recently, related uncertainty about the effectiveness of  
21  
22 435 their medication, were testing out adaptation strategies and were less likely to describe the  
23  
24 436 positive influences of outside support.  
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440 Those patients that described moderate or severe disease activity, symptoms and impact, also  
441 frequently described a non-normal life. Again, several of these patients were recently  
442 diagnosed, and were less certain about the effectiveness of medication in controlling disease  
443 activity and symptoms. Only one of these patients, diagnosed over 10 years prior to interview  
444 detailed a long period of normality whilst medication controlled symptoms and prevented flare  
445 ups. More recently, with frequent flares this patient described her life as a 'rollercoaster' with  
446 periods of severe disruption (flare ups) and intervening remission:

447

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3 448 *“It is a bit like a rollercoaster, there’s like it can be relatively stable for a while, but a flare*  
4  
5  
6 449 *to me is when I start to lose blood and the urgency starts to creep up, and I find it*  
7  
8  
9 450 *difficult to like I say get out of the house in the morning and I have to use the toilet*  
10  
11 451 *frequently at work, or if I’m out, and they’re specifically my flare up symptoms, and it’s*  
12  
13 452 *usually always with passing blood as well, and like I said probably about three of those*  
14  
15  
16 453 *where I’ve been really bad over the past 12 months” (Patient 3)*  
17

18 454  
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20  
21 455 In contrast, four patients whom we interviewed, despite perceptions of more severe disease  
22  
23 456 and flare ups, talked about life with UC in a manner concordant with regaining a sense of a  
24  
25  
26 457 normality. All but one had lived with UC for over 10 years and whilst they were unsure about  
27  
28 458 the effectiveness of their medication in controlling symptoms and flare ups, the use of  
29  
30  
31 459 adaptation strategies and descriptions of positive outside support suggested that over time  
32  
33 460 they had been able to adapt to a life accommodating UC. For example, patient 19 adapted her  
34  
35  
36 461 working hours to be less tired:  
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38 462  
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40  
41 463 *“I also changed my hours, when I had my [previous/most severe] flare up three years*  
42  
43 464 *ago, I do 22 hours, and I used to do it in three days, so I would come in at half eight, and*  
44  
45  
46 465 *eight o’clock in the morning, and I wouldn’t finish until half four, I would have half an*  
47  
48  
49 466 *hour for lunch. After I was last ill it was easy for me to change my hours, and I do the*  
50  
51 467 *same hours, but instead of doing it in three long days I do four short days, because for*  
52  
53 468 *me it’s just easier, so then when I start to get tired I think well I’m going home mid-*  
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3 469 *afternoon, which is why I finish at half two, because it's easier for me physically to cope*  
4  
5  
6 470 *with that, and mentally it's much easier"* (Patient 19)  
7

8 471  
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10  
11 472 Another participant described how his wife had been key in providing emotional and practical  
12  
13 473 support to help with adaptation:  
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16  
17 474 *"I think the physical support, having somebody to lean on, you don't realise it at the time*  
18  
19 475 *when you're on your own that you've just got... obviously got family around you but*  
20  
21 476 *nobody directly in your life, in your house. I think just that moral and physical support*  
22  
23 477 *there is a help, every little helps, it's only a small percentage, it's a definite help"* (Patient  
24  
25 478 26)  
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## 32 480 **Time**

33  
34 481 Participants' accounts and descriptions of attempts to adapt to UC since diagnosis demonstrate  
35  
36 482 that this is an iterative and ongoing process of trial and error. People test the boundaries of  
37  
38 483 abilities and the role of adaptation methods and may take time to gain the necessary  
39  
40 484 facilitators to adaptation, and also to reach a point of acceptance of the disease or not.  
41  
42 485 Similarly, the role of medical therapies in improving physical wellbeing is often reported as  
43  
44 486 being tested iteratively over time in collaboration with healthcare professionals. Finally,  
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46 487 circumstances may change over time, such as the frequency and severity of flares.  
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## 54 489 **DISCUSSION**

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3 490 To our knowledge, this is the first paper in UC and the IBD sphere to propose a framework of  
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6 491 normality (Figure 1) to categorise and understand patients' overall experience of life with the  
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8  
9 492 disease, and the factors that influence adaptation to it. The concept of disease-related  
10  
11 493 normality helps us to think about how disease impacts on patients holistically; the interplay of  
12  
13 494 physical symptoms; the consequences for daily life; and how patients see themselves and their  
14  
15  
16 495 lives as a result. It shows how disease can be a disrupting life experience (the 'non-normal  
17  
18 496 life'), and how patients approach adaptation and whether, broadly speaking, they are  
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20  
21 497 successful in this (the 'normal-life'). In the absence of cure, disease symptoms, adaptation  
22  
23 498 strategies and outside support cumulate to influence patients' views on life with the disease.  
24  
25  
26 499 This can change over time, with acceptance of the disease and need to adapt, and with  
27  
28 500 changing circumstances, such as treatment, disease progression and the presence or absence of  
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31 501 outside support.

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33 502  
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36 503 For patients with UC to be able to live a 'normal life', traditional medical management is likely  
37  
38 504 to be important but as highlighted in this sample, may be insufficient on its own. The majority  
39  
40  
41 505 of patients described other adaptation methods that they felt were required, that they had  
42  
43 506 tried and tested, or were in the process of testing. These methods aimed to achieve different  
44  
45  
46 507 but interrelated things; physical and psychological wellbeing; the ability to carry on working and  
47  
48 508 to prevent embarrassment. There may not be good evidence that the aims of the adaptation  
49  
50  
51 509 strategies can be achieved by the specific methods adopted by patients. As we have described,  
52  
53 510 patients themselves often actively reflect on the efficacy of their actions, for example, in  
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56 511 monitoring and adjusting diet to influence physical wellbeing. Despite this, the trial and error  
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3 512 adoption of different strategies may in itself be important as part of a process of  
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6 513 accommodating disease and being active in doing so. Research in diabetes<sup>29</sup> has proposed that  
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8 514 such actions are important for young people in attempting to 'master' their disease, and recent  
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10  
11 515 research around normality in cancer survivorship<sup>30</sup> has also indicated that the act of doing  
12  
13 516 things is important in its own right regardless of the outcome of the action itself.  
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16 517  
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18 518 It was also clear that adaptation and normality were specific to the individual, meaning  
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21 519 different things to different people. Re-formulating identity and sense of self with disease is  
22  
23 520 crucial for adaptation. Loss of sense of self has been identified as integral to chronic disease  
24  
25 521 experience generally,<sup>31</sup> and other researchers interested in normality in IBD have also observed  
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28 522 that identity influences views on normality.<sup>9,15,17</sup> For a normal life to be achieved, the disease  
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31 523 and its impacts have to be accommodated via adaptation, and thereby integrated into a new,  
32  
33 524 and perhaps dynamic, sense of self. We did not talk to anyone with UC who described their life  
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36 525 as being the same as before the onset of disease. However, for many, the physical burden of  
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38 526 disease will preclude this adaptation and for others there may be a significant period of time  
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41 527 before adaptation is achieved.  
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44 528  
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46 529 The in-depth participant-focused qualitative research approach used here has allowed us to  
47  
48 530 gather and analyse rich and detailed accounts of patients' perspectives on living with and  
49  
50  
51 531 adapting to UC. We have talked to a range of patients who have lived with UC for varying  
52  
53 532 periods of time. There are however limitations to our approach. All of the patients interviewed  
54  
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56 533 were participating in a pilot trial and as such the range of patients was influenced by the trial  
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3 534 eligibility criteria. This meant for example that everybody was in remission at the time of the  
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6 535 interview. Those with longstanding mild and controlled disease were less likely to figure in this  
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8  
9 536 research as patients had to have had a relapse within the 12 months preceding recruitment.  
10  
11 537 However, these are potentially the patients most likely to be able to adapt. Additionally this  
12  
13 538 research is cross-sectional in nature and so we have not been able to observe the temporal  
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16 539 components of adaptation over time, although we have interviewed patients who have been  
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18  
19 540 diagnosed with UC between 1 and 22 years. Further research with a broader range of patients  
20  
21 541 and perhaps with a longitudinal design may provide further insight.  
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23 542  
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26 543 Several patients commented that they had welcomed the opportunity to talk about their views  
27  
28 544 in-depth to someone outside of the clinical team. A few of them said that they felt that their  
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31 545 clinicians were not always receptive to the broader context that they were able to talk about as  
32  
33 546 participants in this research. The implications of this for clinical practice need to be explored  
34  
35  
36 547 further. Naturally, clinicians may focus on the physical and clinical manifestation of disease. As  
37  
38 548 described here, physical wellbeing is a core component of adaptation and a 'normal life'.  
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40  
41 549 However, physical disease and its impacts are experienced holistically by patients and those  
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43  
44 550 around them. The efficacy of medical and surgical management and patients' relationship to  
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46 551 this e.g. via adherence, shared decision-making re treatment options, and interactions with  
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48  
49 552 healthcare professionals and services, will be judged by patients within the broader context of  
50  
51 553 adaptation that we have described here. Other authors have recently reflected on the need to  
52  
53 554 identify and address poor adaptation to IBD as a means to impact on quality of life and also  
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56 555 potentially the course of disease.<sup>32</sup> The consideration and development of interventions that  
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3 556 facilitate adaptation and self-management in UC may help to reflect the holistic experience and  
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6 557 priorities of UC patients.  
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## 10 559 **CONCLUSION**

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13 560 In this study, we have described the views of patients, who for the most part did not use  
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16 561 biologics, on the factors that influence their adaptation to UC and whether they perceived that  
17  
18 562 they are able to regain and maintain a 'normal life'. We have shown that adaptation to UC is  
19  
20  
21 563 complex and that medication alone is most often insufficient to achieve this. Symptoms,  
22  
23 564 adaptation strategies and outside support all have an influence on whether patients manage to  
24  
25  
26 565 regain and maintain normality over time. This holistic view of adaptation to UC will help  
27  
28 566 clinicians and researchers to understand patients' views on life with the disease and the role of  
29  
30  
31 567 medical and other therapies within this.  
32

33 568  
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3 578 **Contributions**  
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5  
6 579 All authors made a substantial contribution to the manuscript. JM designed and conceived the  
7  
8 580 qualitative research with TP. CM (Research Fellow) conducted the interviews. Data analysis was  
9  
10 581 carried out by CM, JM and LJ, and interpretations checked with all authors. The manuscript was  
11  
12 582 drafted jointly by CM and JM. All authors revised the manuscript for intellectual content. All  
13  
14 583 authors have read and approved the final manuscript.  
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20  
21 585 **Patient consent**  
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23 586 Obtained.  
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27  
28 588 **Data sharing statement**  
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30  
31 589 No additional data are available.  
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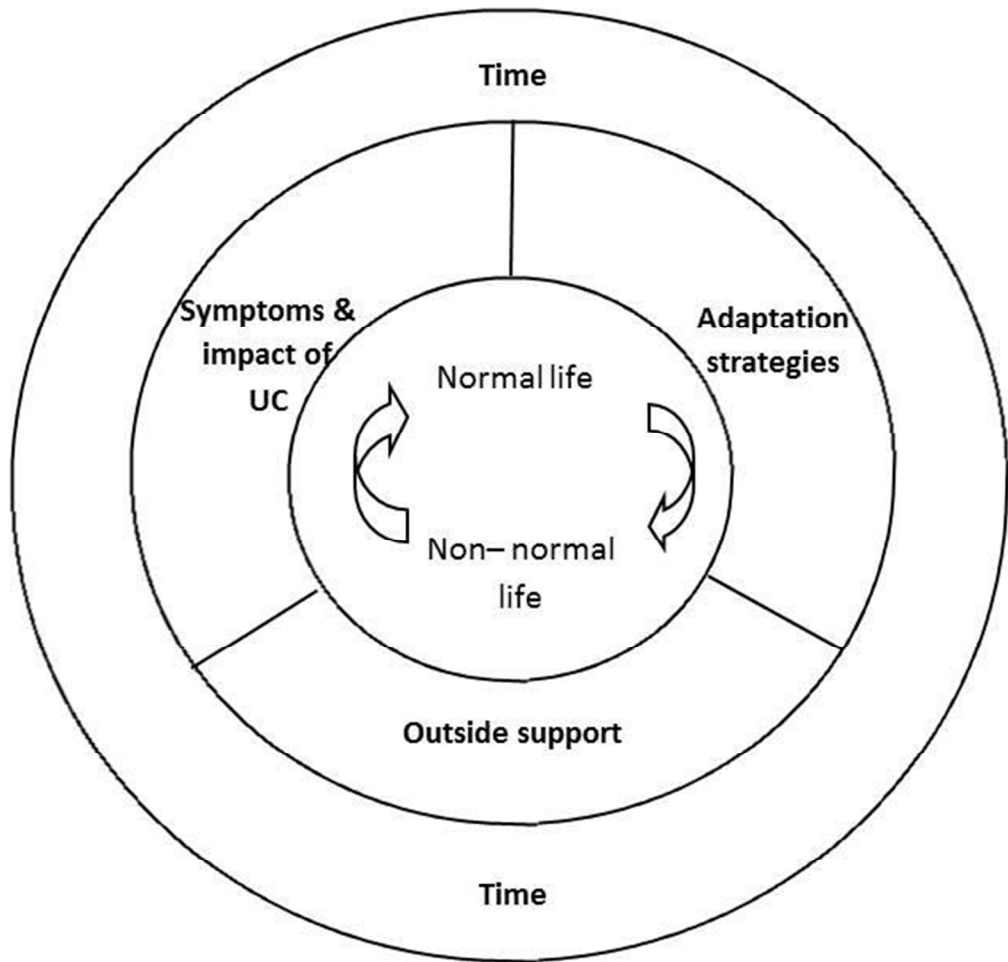
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6 673 **FIGURE LEGEND**  
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8 674 Figure 1 – Influences on normality in ulcerative colitis  
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Influences on normality in ulcerative colitis

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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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# BMJ Open

## Adapting to ulcerative colitis to try to live a 'normal' life: a qualitative study of patients' experiences in the Midlands region of England

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017544.R2
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Date Submitted by the Author:	28-Jun-2017
Complete List of Authors:	McMullan, Christel; University of Birmingham, Institute of Applied Health Research Pinkney, Tom; University of Birmingham, Academic Department of Surgery Jones, Laura; University of Birmingham, Institute of Applied Health Research Magill, Laura ; University of Birmingham, Birmingham Clinical Trials Unit Nepogodiev, Dmitri; University of Birmingham, Academic Department of Surgery Pathmakanthan, Shri; University Hospitals Birmingham NHS Foundation Trust, Department of Gastroenterology Cooney, Rachel; University Hospitals Birmingham NHS Foundation Trust, Department of Gastroenterology Mathers, Jonathan; University of Birmingham, Institute of Applied Health Research
<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Gastroenterology and hepatology, Qualitative research
Keywords:	QUALITATIVE RESEARCH, ulcerative colitis, adaptation, normality, Gastroenterology < INTERNAL MEDICINE

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Manuscripts

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3 1 **Adapting to ulcerative colitis to try to live a 'normal' life: a qualitative study of patients'**  
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6 2 **experiences in the Midlands region of England**  
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6 28 **ABSTRACT**  
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11 30 **Objective**  
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13 31 To provide a framework that is able to categorise whether patients are able to adapt to and  
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16 32 lead a 'normal' life with ulcerative colitis (UC) and to detail the factors that influence this.  
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21 34 **Design**  
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23 35 Qualitative research study using in-depth semi-structured interviews.  
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28 37 **Setting**  
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31 38 Four clinical sites in the West and East Midlands regions of England.  
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36 40 **Participants**  
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38 41 28 adult patients diagnosed with UC for between 1 and 22 years.  
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41 42  
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43 43 **Results**  
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46 44 Medication was rarely sufficient for patients to adapt to UC and live as 'normal' a life as  
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48 45 possible. Virtually all patients tested and adopted non-medical adaptation methods to improve  
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51 46 physical and psychological wellbeing, to help them carry on working, and to prevent  
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53 47 embarrassment. In addition, some patients benefited from outside support, providing them  
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56 48 with practical, emotional, and/or financial help. In conjunction with adaptation strategies and  
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3 49 the time to adapt, this meant that some patients with severe clinical disease were able to  
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6 50 maintain a sense of normality in life. Patients reported that clinicians were not always  
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9 51 receptive to discussion of the broader context of life with UC.

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### 13 53 **Conclusions**

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16 54 Patients' experience of UC and their ability to adapt in order to maintain a sense of normality in  
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19 55 life is a complex interplay of symptoms, adaptation strategies and outside support. Over time  
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21 56 patients test out a variety of non-medical adaptation strategies. Awareness of this may help  
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24 57 clinicians and researchers to understand patients' views on the role of medical and other  
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26 58 therapies. Further research around the utility of this framework in clinical practice and  
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29 59 research is now required.

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### 33 61 **Strengths and limitations of this study**

- 34  
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36 62 • This study is an in-depth participant-focused qualitative study providing rich and detailed  
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39 63 accounts of patients' experiences of living with and adapting to UC.
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41 64 • This is the first detailed analysis that has attempted to categorise whether patients are able  
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44 65 to adapt to and lead a 'normal' life with UC, and also to detail the factors that influence  
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46 66 this.
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49 67 • The semi-structured interviews provided patients the opportunity to talk about their  
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52 68 experience to someone outside of their clinical team.
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54 69 • The research is cross-sectional in nature, limiting the potential to observe the temporal  
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57 70 components of adaptation over time.
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3 71 • The patients interviewed were participating in a pilot trial, which means that the range of  
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6 72 patients was influenced by the trial eligibility criteria.  
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11 **Funding**

12  
13 75 This work was supported by a grant from the Research for Patient Benefit (RfPB) programme of  
14  
15  
16 76 the National Institute for Health Research (NIHR) (grant number - ISRCTN56523019).  
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18 77  
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21 **Competing interests**

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23 79 The authors confirm that they have no conflict of interest to disclose.  
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6 83**INTRODUCTION**

84 Ulcerative colitis (UC) is a form of chronic inflammatory bowel disease (IBD) which affects the  
85 large bowel. Over 145,000 people in the UK<sup>1</sup> and 900,000 in the USA<sup>2</sup> are living with UC. The  
86 condition is most prevalent in Northern Europe and North America, although the number of  
87 people affected by UC is increasing recently in developing countries.<sup>3</sup> There is also an  
88 increasing incidence of UC among younger patients.<sup>4</sup> Around 40% of patients will experience a  
89 relapse annually, with between 20% and 30% requiring total colectomy in their lifetime.<sup>5,6</sup>  
90 Reducing relapse rates and disease progression is a priority for patients.<sup>7</sup> Ulcerative colitis has  
91 been shown to have a significant negative impact on Health-Related Quality of Life (HRQoL).<sup>8</sup>  
92 Whilst many patients' lives are severely disrupted as, for example, the disease affects their  
93 ability to work as well as their social and family life,<sup>8-11</sup> these impacts are not always directly  
94 correlated, from a clinical perspective, with disease activity and severity of symptoms.<sup>12</sup>  
95 Patients with mild clinical disease can experience significant impacts on HRQoL and  
96 psychological morbidity, whilst some with apparently severe disease activity seem to 'cope'  
97 relatively well.

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99 Commentators have argued that often the focus of the medical management of IBD is too much  
100 on acute episodes, not necessarily reflecting the chronicity of IBD and therefore the overall  
101 patient experience of disease over time.<sup>13</sup> Understanding more about living with IBD can help  
102 to highlight the role that medical and surgical management plays. The patient perspective on



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3 103 living with UC may sometimes be difficult for clinicians to interpret as they may underestimate  
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6 104 or overlook the overall effects of disease on patients' lives.<sup>8</sup>

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11 106 Qualitative research is well placed to describe and understand patients' views on disease and  
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13 107 treatment.<sup>14</sup> Within IBD and UC there is a small but informative body of qualitative research  
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16 108 relevant to these issues and work to date has described patients' perspectives on the impact of  
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18 109 IBD; of the physical symptoms, and broader issues, for example, on work, lifestyle, daily  
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21 110 activities, social life, and psychological well-being.<sup>8-11,15-20</sup> Research has suggested that patients  
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23 111 are engaged in a 'fight' for some sort of health-related normality and that achieving a 'new  
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26 112 normal' is their ultimate goal.<sup>15</sup> Trying to live as 'normal' a life as possible is something that  
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28 113 patients reflect upon when they talk about life with IBD.<sup>12</sup> This body of research describes  
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31 114 patients' views on how their lives are affected by IBD and shows that adaptation (i.e. a desire  
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33 115 for normality) is an overriding concern. However, to date nobody has provided a clear  
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36 116 framework to help understand normality and adaptation in UC.

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41 118 The aim of this paper is therefore twofold; (1) to provide a framework that is able to categorise  
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43 119 whether patients are able to adapt to and lead a 'normal' life with UC and (2) to detail the  
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46 120 factors that influence this.

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## 51 122 **METHODS**

### 53 123 **Setting and study design**

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3 124 Participants were recruited from four hospitals in the West and East Midland regions of England  
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6 125 and were taking part in the National Institute for Health Research (NIHR) Research for Patient  
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8 126 Benefit-funded ACCURE-UK trial.<sup>21</sup> This randomised external pilot trial was exploring the  
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10 127 feasibility of a multi-centre randomised controlled trial (RCT) of therapeutic appendicectomy  
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12 128 for the treatment of UC (intervention arm) in addition to standardised medical therapy (control  
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14 129 arm). The trial included integrated qualitative research, the main aim of which was to  
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16 130 investigate the acceptability of the trial and understand this within the context of patients'  
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18 131 everyday lives with UC.  
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23 132 The theoretical underpinnings of our approach most closely align with interpretive description.  
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25 133 Originally described in nursing and drawing on methods from established qualitative  
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27 134 methodologies this approach has a heavy emphasis on understanding and informing clinical  
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29 135 practice.<sup>22,23</sup> The research methods we describe (e.g. for interviews – broad purposive  
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31 136 sampling, iterative in-depth data collection and inductive analysis without a priori theoretical  
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33 137 tools) are concordant with a generic interpretive approach to addressing our research aims.  
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### 41 139 **Sampling and recruitment**

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43 140 We recruited a diverse sample (age, gender, time since diagnosis) of patients from both arms of  
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45 141 the pilot RCT. Clinical staff initially discussed the qualitative research with patients. With  
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47 142 consent, the contact details of patients expressing an interest were passed to the researcher  
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49 143 conducting the interviews (CM), who then took informed consent prior to interview.  
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### 54 55 56 145 **Data collection**

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3 146 Semi-structured one-to-one interviews were conducted by CM between randomisation and  
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6 147 surgery for those allocated to intervention arm, and shortly after randomisation for those in the  
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9 148 control arm. CM is a non-clinical trained qualitative researcher independent from participants'  
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11 149 clinical care and the day-to-day trial management. This was clearly communicated to  
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14 150 participants. Participants were asked to select a convenient time and place for interview. Most  
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16 151 chose to be interviewed at home, although a small number of interviews were conducted on  
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19 152 hospital or university premises, or by telephone.

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23 154 The interview schedule was informed by the existing literature and consultation with the wider  
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26 155 research team. It included discussion of patients' views and experience of life with UC since  
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29 156 initial diagnosis: their symptoms, their flare ups and their impacts, their medical treatment, and  
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31 157 their perspectives on adaptation to UC. In addition, a section of the interview focused on  
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34 158 participants' perspectives on the RCT and trial processes (data not reported here). Interviews  
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36 159 were conducted in a participant-focused open-ended manner. After initial piloting, data  
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39 160 collection and analysis took place iteratively. This continued until the research team judged  
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41 161 that the data and sample had sufficient depth and breadth to address initial research  
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44 162 questions.<sup>24</sup> Field notes were kept after the interviews to record factors that might have  
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46 163 influenced the conduct and the analysis of the interviews.

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## 50 51 165 **Data analysis**

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54 166 All interviews were audio-recorded and transcribed verbatim by a specialist external  
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56 167 transcription company. Data were analysed thematically and managed using Computer-Aided  
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3 168 Qualitative Data Analysis Software (CAQDAS), NVivo10. The analysis was informed by the  
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6 169 Framework analytical approach.<sup>25</sup> Firstly, interview transcripts were reviewed several times and  
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9 170 open coding was undertaken. These codes were then reviewed and categorised and the  
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11 171 dataset indexed. Categories were refined into overarching themes from descriptive accounts of  
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13 172 the data. Final analysis and explanation was facilitated by use of a typology and associative  
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16 173 analysis using charting. The analytic typology is described in more detail below. A sample of  
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18 174 interviews were coded by an independent researcher during initial coding. The research team  
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21 175 ensure not only that code saturation was reached but also that we had a deep and rich  
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23 176 understanding of that the themes derived during analysis were about.<sup>26</sup> The final analysis and  
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26 177 interpretation were discussed amongst the research team, and with one patient who took part  
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28 178 in the interviews.

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### 32 33 180 **Analytic typology**

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36 181 During analysis we have applied a typology devised from qualitative data gathered with  
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38 182 patients with rheumatoid arthritis, another chronic inflammatory disease of relapsing remitting  
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41 183 nature.<sup>27</sup> A typology is a classification system that consists of categories that describe different  
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43 184 types of a phenomenon of interest; here adaptation to life with UC and the ability to attain a  
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46 185 new sense of normality. Typologies are sometimes used to categorise observations in  
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48 186 qualitative data.<sup>28</sup>

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51 187 In addressing our first research aim we have categorised participants into two types (see Table  
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53 188 1 & Table 2), one of broadly positive experience and adaptation to UC ('the normal life') and  
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56 189 one of negative experience and non-adaptation ('the non-normal life'). This typology  
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3 190 encompasses patients' reactions to their illness, their attempts to adapt to it, and success or  
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6 191 failure in this. Of note, these are not static categorisations; patients may move between them,  
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9 192 over time, and as a consequence of changing circumstances. We have used the accounts given  
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11 193 by participants during the interviews to assign them to these two broad categories, at the time  
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13 194 of the interview, and at time points since diagnosis.  
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Type / category	Definition and constituent elements
Non-normal life	<ul style="list-style-type: none"> <li>• Some people may find it difficult to accept their condition and attempt to carry on as before, even hiding their condition from others. This may have negative consequences when this is not successful</li> <li>• Symptoms may be devastatingly intrusive and unmanageable for some. It may be difficult or impossible to carry out day-to-day activities, for example, because of symptoms and/or embarrassment, despite acknowledging and trying to adapt to the condition</li> <li>• The condition can threaten peoples' self-identity and associated sense of normality</li> <li>• There may be a feeling of loss of control over the disease and life</li> </ul>
	<ul style="list-style-type: none"> <li>• For some, medication may be so effective that they can carry on as normal i.e. as before the diagnosis</li> </ul>

Normal life	<ul style="list-style-type: none"> <li>• Other patients may experience mild symptoms with minimal impact on life, daily activities and self-identity, with control facilitated by medication</li> <li>• Some patients with more severe symptoms may reconceptualise normal life by including their condition and its impacts in a life that accommodates the disease. This will include acceptance of the condition and re-orientation of self-identity and thoughts about what constitutes a healthy body</li> </ul>
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196 *Table 1 – Normality types - adapted from Sanderson et al. (2011)*

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## 198 **ETHICAL CONSIDERATIONS**

199 Ethical approval for the ACCURE-UK trial was granted from the North East Tyne and Wear South  
 200 Research Ethics Committee, REC number 14/NE/1143.

201

## 202 **RESULTS**

203 The following analysis is based on data from interviews with 28 patients (Table 2), which lasted  
 204 between 22 and 58 minutes; 16 women and 12 men aged between 18 and 57; 24 of white and  
 205 4 of Asian ethnic origin; diagnosed with UC between 1 and 22 years. All were in remission at  
 206 the time of interview but had experienced a disease relapse within the preceding 12 months  
 207 (RCT eligibility criteria). All but one were on medical therapy, with three having taken biologic  
 208 therapies, such as infliximab and adalimumab. One patient had decided to discontinue all  
 209 medical therapy due to side effects. None had undergone any colonic surgery previously. There  
 210 was no withdrawal.

211

Patient ID	Age	Year of diagnosis	Marital status	Employment status	Disease severity (Mild, Moderate or Severe) <sup>a</sup>	Current medication regime <sup>b</sup>	Dominant type of normality at interview	Previous period of normality described (non-normal life only) <sup>c</sup>	Adaptation strategies used <sup>c</sup>	Outside support described <sup>c</sup>
1	31-40	2004	Married	Self-employed	Moderate/Severe	5-ASA, Immunomodulators	Non-normal	N	Y	N
2	31-40	2013	Married	Employed	Mild	5-ASA, Immunomodulators	Non-normal	N	Y	N
3	31-40	2003	Married	Employed	Moderate	5-ASA, Immunomodulators	Non-normal	Y	Y	Y
4	21-30	2014	Cohabiting	Employed	Mild	5-ASA, Immunomodulators	Non-normal	N	Y	Y
5	51-60	2009	Married	Not employed	Moderate	5-ASA, Immunomodulators	Non-normal	N	Y	Y

6	31-40	2013	Married	Employed	Moderate/Severe	5-ASA, Immunomodulators	Non-normal	N	Y	Y
7	41-50	2012	Single	Self- employed	Mild	5-ASA,	Non-normal	N	Y	N
8	21-30	2009	Single	Employed	Moderate	5-ASA, Immunomodulators	Non-normal	N	Y	Y
9	21-30	2011	Single	Employed	Mild	5-ASA, Biologics	Normal	N/A	Y	Y
10	51-60	2014	Divorced	Self- employed	Moderate	5-ASA	Non-normal	N	Y	N
11	31-40	2002	Single	Employed	Mild	5-ASA	Non-normal	Y	Y	N
12	41-50	2013	Divorced	Self- employed	Mild	5-ASA	Normal	N/A	Y	N
13	21-30	2013	Single	Employed	Mild	5-ASA	Normal	N/A	Y	Y
14	21-30	2014	Single	Employed	Moderate	Immunomodulators, Biologics	Non-normal	N	Y	N



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15	31-40	1995	Single	Employed	Moderate	5-ASA, Immunomodulators	Normal	N/A	Y	Y
16	21-30	2014	Single	Employed	Moderate	5-ASA, Immunomodulators	Non-normal	N	Y	Y
17	31-40	2006	Single	Employed	Mild	5-ASA, Immunomodulators	Normal	N/A	Y	N
18	51-60	2014	Separated	Not known	Mild	5-ASA	Normal	N/A	Y	N
19	41-50	2003	Married	Employed	Moderate	5-ASA,	Normal	N/A	Y	Y
20	<20	2014	Single	Unemployed	Mild/Moderate	5-ASA	Non-normal	N	Y (medication only)	Y
21	41-50	2012	Married	Self- employed	Moderate/Severe	5-ASA, Immunomodulators	Non-normal	N	Y	Y
22	41-50	1993	Married	Employed	Mild	5-ASA	Normal	N/A	Y	N
23	21-30	2014	Cohabiting	Employed	Mild	5-ASA	Normal	N/A	Y	Y

									(medication only)	
24	41-50	2003	Married	Employed	Mild	None	Normal	N/A	Y	Y
25	41-40	2013	Married	Employed	Mild	5-ASA, Immunomodulators	Non-normal	N	Y	N
26	51-60	2004	Married	Employed	Moderate	5-ASA, Immunomodulators	Normal	N/A	Y	Y
27	31-40	2011	Married	Employed	Mild/Moderate	5-ASA, Immunomodulators, Biologics	Normal	N/A	Y	Y
28	31-40	2013	Married	Employed	Moderate	5-ASA, Immunomodulators	Non-normal	N	Y	N

212 **Table 2 - Sample characteristics including normality types, adaptation strategies and outside support**

213 <sup>a</sup>Disease severity was categorised based on patients' descriptions of their symptoms and through analysis of this and descriptions of the impacts of UC that  
 214 patients provided e.g. the amount of time patients took off work, and the number of flare ups patients described.

215 **b** Categorical data on type of medication at time of interview

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216 Y = Yes, N = No

For peer review only

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6 218 Findings are presented as follows:

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- 9 219 • the normality types experienced and described by our participants
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- 11 220 • their adaptation strategies and intended purpose
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- 13 221 • the outside support to adaptation and;
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- 16 222 • how these factors interact with symptoms to influence the ability of a patient with UC to
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- 19 223 lead a normal life
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24 225 **Participants' descriptions of normal and non-normal life since diagnosis**25  
26 226 Our analysis of patients' accounts suggests that at the point of interview, 12 of the 2827  
28 227 participants in this sample could be categorised as experiencing some form of normal life with29  
30 228 UC. There was no clear relationship between the length of time since diagnosis and the type of31  
32 229 normality they were experiencing at the time of the interview. At diagnosis, all participants had33  
34 230 described a period of non-normal life with significant disruption due to disease activity and35  
36 231 symptoms. Some also talked about a need to understand and acknowledge the significance of37  
38 232 the diagnosis itself. Participants suffered from intrusive symptoms (stomach cramps, bleeding,39  
40 233 more frequent bowel movements) and in many cases it took several months to receive a41  
42 234 definitive diagnosis and treatment, with several patients ending up being admitted to hospital.43  
44 235 As a result, they had to take time off work and were not able to carry on with their daily45  
46 236 activities:  
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3 238 *“Diagnosed in October. We were actually away in Spain when I had the flare up, and I*  
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6 239 *was in hospital in Spain for a week, and they did all the tests there, then when I got back*  
7  
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9 240 *to England they did it all again in October. I was due to go in for the camera, and when I*  
10  
11 241 *got there they said that I’d got so weak that they wouldn’t be able to do it, but they kept*  
12  
13 242 *me in, and obviously I was in hospital then for three weeks, or nearly four weeks I believe*  
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16 243 *it was at the time”* (Patient 18)  
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21 245 Following an initial period of disruption and non-normal life around the time of diagnosis  
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23 246 participants’ accounts vary, with some seemingly not having attained or regained any sense of a  
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25  
26 247 normal life. Others had managed to do so, some temporarily. Only three patients described a  
27  
28 248 period where they felt that they had been relatively unaffected as their symptoms were largely  
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31 249 controlled by medication, such that they were able to carry on life without much perceived  
32  
33 250 impact. For example, one male participant who was diagnosed in 2002 talked about not having  
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36 251 a flare up whilst managing UC for the first five years with medication. None of the participants  
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38 252 indicated that medication had dealt with all of their symptoms to the extent that life was the  
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41 253 same as before the onset of disease.  
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#### 255 **Participants’ descriptions of adaptation strategies and their intended purpose**

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48 256 During the interviews all participants described attempts to adapt to their condition, and all but  
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51 257 two participants actively tested or adopted approaches that were additional to medical  
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53 258 therapies. We have categorised the adaptation strategies described according to their  
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56 259 intended purpose. Most commonly participants aimed to achieve four things (Table 3):  
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261 • To improve physical wellbeing

262 • To improve psychological wellbeing

263 • To carry on working

264 • To prevent embarrassment

265

Aims of adaptation	Adaptation strategies
Improve physical wellbeing (reduce symptoms and flare ups; prevent triggers of flare ups)	Medication  Change diet  Probiotic use  Complementary therapies (e.g. acupuncture, hypnotherapy)  Finding a balance between doing too much and too little (pacing)  Exercise  Yoga  Relaxation classes  Smoking  Personal research (inc. forums, Crohn's and

	Colitis UK, social media)
Improving psychological wellbeing	<p>Positive and proactive attitude</p> <p>Fighting on / soldiering on in activities (e.g. playing netball, going on holiday)</p> <p>Finding a balance between doing too much and too little (pacing)</p> <p>Mindfulness courses</p> <p>Yoga</p> <p>Relaxation classes</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
Carry on working	<p>Reducing working hours; selling off part of own business</p> <p>Rearranging working patterns</p> <p>Changing jobs</p> <p>Getting up earlier</p>

	<p>Finding a balance between doing too much and too little (pacing)</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>
Prevent embarrassment	<p>Situational avoidance (not going out; avoiding certain places)</p> <p>Planning (timing, location, duration of activities)</p> <p>Wearing nappies</p> <p>Personal research (inc. forums, Crohn's and Colitis UK, social media)</p>

266 *Table 3 – Adaptation strategies and aims<sup>a</sup>*

267 <sup>a</sup>A number of adaptation methods appear across several categories

268

269 Improve physical wellbeing

270 This category describes participants' strategies to reduce physical symptoms and the frequency  
 271 of UC flare ups, and also to do so by addressing perceived triggers of flare ups. The physical  
 272 symptoms were a very important part of the great majority of patients' accounts, as they made  
 273 them extremely fatigued:

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3 275 *“Just draining, not tired, not sleepy, just drained. [Name] knows what I’m like, by the*  
4  
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6 276 *time I’ve been five times and I’ve just got no energy, just no energy to do anything, and I*  
7  
8 277 *just the best thing is just to give into it. I say to [name], you’re going to have to count me*  
9  
10 278 *out for the rest of the day, and just give into it” (Patient 21)*

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13 279  
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16 280 The most common adaptation approach in this category was medication, with all but one  
17  
18 281 participant taking regular medication to improve physical wellbeing. The one participant, who  
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20  
21 282 had ceased taking medication due to side effects, reported that smoking helped to reduce  
22  
23 283 symptoms. During the interviews it was clear that there were varied perspectives on whether  
24  
25  
26 284 medication was ‘working’. Some reported that medication was effective and others that it was  
27  
28 285 not. Some participants were unsure as to how much it helped:

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31 286  
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33 287 *“I don’t notice any effect with the anti-inflammatories (...) It generally doesn’t keep it*  
34  
35 288 *[UC] away, because like I say I can be fully recovered, go nine/ten months of the year*  
36  
37 289 *whilst taking anti-inflammatories every day, and still go into a flare up. But whether if I*  
38  
39 290 *didn’t take them I don’t know if I’d go into a flare up quicker. So I don’t know” (Patient*  
40  
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42  
43 291 *1)*

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48 293 Another common adaptation approach to improve physical wellbeing was to change diet. As  
49  
50 294 with other adaptation approaches, this was often a trial and error strategy with the aim to  
51  
52 295 establish which foods tended to worsen symptoms or trigger flares. Some people reported  
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3 296 keeping a food diary for several weeks or months to identify patterns in their food intake and  
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6 297 symptoms:

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10 299 *“When I came out of hospital for about a month I kept a list of all the food I’d eaten*  
11  
12 *every day and what I’d drank, so that if I went into a flare up I could look back and say*  
13 300  
14 *maybe it was that, so I’ll try it one more time and if it happens again I’ll not eat or drink*  
15 301  
16 *that again”* (Patient 10)  
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23 304 Other adaptation strategies in this category include the use of complementary therapies (e.g.  
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25 acupuncture or hypnotherapy), exercise, yoga, relaxation courses to avoid triggers (stress), and  
26 305  
27 the pacing of activities to find a balance between symptoms and the ability to do things.  
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31 307

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33 308 Improve psychological wellbeing

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36 309 When discussing issues pertaining to psychological wellbeing several participants stated that  
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38 310 they have a positive and proactive outlook on life with UC. We believe that this signals  
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40 acceptance that the disease was not going to go away, and describes an associated attitude and  
41 311  
42 approach to living with it. This was sometimes evident in discussions about the need to ‘soldier  
43 312  
44 on’ and maintain some or all of the activities that participants pursued prior to diagnosis, such  
45 313  
46 as playing sports, going out, and going on holiday. Often, similar to other adaptations, this  
47 314  
48 would involve a process of testing the boundaries of what was possible and finding a balance  
49 315  
50 between the desire to keep going and the potential negative (e.g. physical) consequences of  
51 316  
52 doing too much. For example, Patient 19, a 42 year old woman first diagnosed in 2003  
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3 318 described how, over the years, she adapted her activities to have more control of her condition,  
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6 319 but was keen not to be a 'victim', which she likened to being 'too depressive':  
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11 321 *"I just refuse to give up and not do anything, and I know that the exercise is good for me.*  
12  
13 322 *But equally I know that doing too much exercise is bad for me, because it will make me ill*  
14  
15 323 *and run down (...) refusing to not do anything and be a victim and just sit at home doing*  
16  
17 324 *nothing, because that's just too depressing to even think about isn't it?" (Patient 19)*  
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23 326 Specific activities that were adopted by participants in an attempt to improve psychological  
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26 327 wellbeing included attending mindfulness and relaxation courses, and also yoga.  
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31 329 Carry on working  
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33 330 Being able to maintain a working life was expressed as a key concern by the majority of our  
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36 331 participants. The main strategy in order to carry on working was reducing working hours,  
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38 332 because of fatigue (one of the most commonly reported physical symptoms), a lack of  
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41 333 concentration and the need to constantly be near toilets. Spending less time in work meant  
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44 334 that participants had more time for themselves to rest at home:  
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48 336 *"There's certain things I can't do at work, like I don't do playground duty, because that*  
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51 337 *way I get an extra break, I don't teach PE, it just wears me out really, it is quite a physical*  
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53 338 *job. I've had to reduce my days as well, I did work three days a week before I was*  
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56 339 *diagnosed, and now I only work two"* (Patient 6)  
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6 341 Participants who reduced their working hours found themselves to be more efficient at work.  
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9 342 However, this had a financial impact, placing burden on participants and their families.  
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11 343 Other strategies to maintain working included rearranging working patterns (e.g. working only  
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13 344 in the afternoon as symptoms were worse in the morning; spreading working hours throughout  
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16 345 the week), changing jobs to something less demanding, and getting up earlier in the morning to  
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18 346 have more time to deal with the symptoms and be ready in time for work.  
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23 348 Prevent embarrassment  
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26 349 Avoiding and preventing the embarrassment potentially caused by UC was a key theme in the  
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28 350 data. This very often restricted participants in their daily life, for example, with the fear of  
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31 351 being embarrassed by not being able to find toilets when needed:  
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36 353 *"I don't go out as much as I did before, and when I go out I'm very nervous, first thing I*  
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38 354 *do a check where is the nearest toilet even if I don't need it, and some days if my friends*  
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41 355 *want to go out or do something I might be too fatigued"* (Patient 4)  
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46 357 One strategy employed to prevent embarrassment was situational avoidance with some  
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48 358 participants reporting not going out or not going to places where toilets are not readily  
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50  
51 359 available. Whilst such avoidance may be perceived as being effective in preventing  
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53 360 embarrassment, in turn it could result in feelings of isolation:  
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3 362 *“Well because I’ve been having so many flare ups and been unwell a lot I don’t have so*  
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6 363 *much of a social life now, and every time I try and plan things in I end up being ill a lot*  
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9 364 *and having to cancel all the time, so I stopped making forward plans now to be honest,*  
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11 365 *because if there are things a few months away I just say to friends that I have to let you*  
12  
13 366 *know at the time, because I never know what my health is going to be like. So it has had*  
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16 367 *quite an impact socially. It can be a bit isolating as well, that’s a bit difficult” (Patient 8)*  
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21 369 Other participants discussed having to carefully plan, such as for nights out, around the location  
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23 370 of the toilets, to limit the frequency of their social outings, or to try to plan them during  
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26 371 remission periods. Finally, one patient reported being able to go out because he was wearing  
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28 372 nappies, which meant he was not as restricted by the location of toilets.  
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31 373  
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33 374 Personal research, including participation in disease-specific internet forums and social media  
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36 375 was described as contributing to each of the aims associated with adaptation strategies that  
37  
38 376 were tested by patients:  
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41 377  
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43 378 *“It’s just a Facebook group of everybody who has got Crohn’s and colitis really, it’s a*  
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45  
46 379 *group where you could obviously speak to other people about your condition. There’s*  
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48  
49 380 *quite a lot of support on there, and it has been mentioned, and so there’s obviously*  
50  
51 381 *people already know already. There seems to be a lot of support for anything,*  
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54 382 *awareness of disease, and look at ways of improving the condition” (Patient 3)*  
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3 384 **Outside support to adaptation**  
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6 385 Some patients spoke about the influence of outside support in enabling life and adaptation to  
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8 386 UC. Such support was not necessarily asked for or actively sought by participants but  
9  
10 387 nevertheless helped them live and manage UC on a day-to-day basis. They provided an  
11  
12 388 invaluable source of social support for several participants.  
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18 390 The main support evident in the data were:  
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21 391 • Help from parents/close family members (practical, emotional, and financial)  
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23 392 • Help from a partner and/or children (practical and emotional)  
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25  
26 393 • Help from friends (practical and emotional)  
27  
28 394 • Help from employer/workplace (practical)  
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33 396 Support from parents and other close family members included moving closer to participants or  
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35 397 having them live with them in order to help with day-to-day tasks e.g. the school run,  
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37 398 household chores, and give them financial help:  
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43 400 *“My parents have moved house to be nearer (...) But they rushed the move because I was*  
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45 401 *poorly, they actually moved while I was in hospital, because while I was in hospital they*  
46  
47 402 *were staying here for half the week to have my boys, because when I was in hospital*  
48  
49 403 *both my boys were preschool age, they were two and four, so obviously someone had to*  
50  
51 404 *have them.” (Patient 6)*  
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3 406 Participants also often discussed the practical and emotional support provided by their partners  
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6 407 and children:  
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11 409 *“Luckily my daughter is quite mature for her age, because she’s only 11, but she does*  
12  
13 410 *understand, and she’s quite good, and she will help me, and if I need help she is always*  
14  
15 411 *there, and make me a cup of tea and little things like that. So yes quite lucky in that*  
16  
17 412 *respect.” (Patient 15)*  
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23 414 Finally, work managers and the workplace often offered practical support to patients, mainly by  
24  
25 415 providing flexible working hours, helping them to attend hospital appointments or deal with the  
26  
27 416 impact of symptoms:  
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33 418 *“Work have been pretty good, been really good with allowing me time off for*  
34  
35 419 *appointments and things.” (Patient 23)*  
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41 421 One patient described how his workplace had recognised UC as a disability, and that this was  
42  
43 422 invaluable in providing the means to accommodate the impacts of the disease e.g. by taking  
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45 423 time off work for hospital appointments or because of symptoms.  
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51 425 **How symptoms, adaptation strategies and outside support interact to influence adaptation**  
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53 426 **and the ability to live a normal life with UC**  
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3 427 Whether patients are able to maintain or regain a sense of a normal life with UC appears to be  
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6 428 a complex interplay between disease activity and symptoms, the impacts of these, attempts to  
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9 429 adapt, and outside support (Figure 1). Those patients who, overall, describe and judge their  
10  
11 430 disease activity to be mild were also more likely to indicate that they were able to regain a  
12  
13 431 sense of normality. Most, but not all of these patients, thought that their medication was  
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15  
16 432 successful in helping them control symptoms and impacts. All but one had adopted some  
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18 433 adaptation strategies and half described the positive influence of outside support. However,  
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21 434 several patients who described mild disease did not convey a sense of a normal life. Most of  
22  
23 435 these had been diagnosed relatively recently, related uncertainty about the effectiveness of  
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25  
26 436 their medication, were testing out adaptation strategies and were less likely to describe the  
27  
28 437 positive influences of outside support.

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33 439 Insert Figure 1

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38 441 Those patients that described moderate or severe disease activity, symptoms and impact, also  
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40  
41 442 frequently described a non-normal life. Again, several of these patients were recently  
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43  
44 443 diagnosed, and were less certain about the effectiveness of medication in controlling disease  
45  
46 444 activity and symptoms. Only one of these patients, diagnosed over 10 years prior to interview  
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48  
49 445 detailed a long period of normality whilst medication controlled symptoms and prevented flare  
50  
51 446 ups. More recently, with frequent flares this patient described her life as a 'rollercoaster' with  
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54 447 periods of severe disruption (flare ups) and intervening remission:

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3 449 *“It is a bit like a rollercoaster, there’s like it can be relatively stable for a while, but a flare*  
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5  
6 450 *to me is when I start to lose blood and the urgency starts to creep up, and I find it*  
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8  
9 451 *difficult to like I say get out of the house in the morning and I have to use the toilet*  
10  
11 452 *frequently at work, or if I’m out, and they’re specifically my flare up symptoms, and it’s*  
12  
13 453 *usually always with passing blood as well, and like I said probably about three of those*  
14  
15  
16 454 *where I’ve been really bad over the past 12 months” (Patient 3)*  
17

18 455  
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20  
21 456 In contrast, four patients whom we interviewed, despite perceptions of more severe disease  
22  
23 457 and flare ups, talked about life with UC in a manner concordant with regaining a sense of a  
24  
25  
26 458 normality. All but one had lived with UC for over 10 years and whilst they were unsure about  
27  
28 459 the effectiveness of their medication in controlling symptoms and flare ups, the use of  
29  
30  
31 460 adaptation strategies and descriptions of positive outside support suggested that over time  
32  
33 461 they had been able to adapt to a life accommodating UC. For example, patient 19 adapted her  
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36 462 working hours to be less tired:  
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38 463  
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41 464 *“I also changed my hours, when I had my [previous/most severe] flare up three years*  
42  
43 465 *ago, I do 22 hours, and I used to do it in three days, so I would come in at half eight, and*  
44  
45  
46 466 *eight o’clock in the morning, and I wouldn’t finish until half four, I would have half an*  
47  
48  
49 467 *hour for lunch. After I was last ill it was easy for me to change my hours, and I do the*  
50  
51 468 *same hours, but instead of doing it in three long days I do four short days, because for*  
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53  
54 469 *me it’s just easier, so then when I start to get tired I think well I’m going home mid-*  
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3 470 *afternoon, which is why I finish at half two, because it's easier for me physically to cope*  
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5  
6 471 *with that, and mentally it's much easier"* (Patient 19)  
7

8 472  
9

10 473 Another participant described how his wife had been key in providing emotional and practical  
11  
12 support to help with adaptation:  
13 474

14  
15  
16  
17 475 *"I think the physical support, having somebody to lean on, you don't realise it at the time*  
18  
19 476 *when you're on your own that you've just got... obviously got family around you but*  
20  
21 477 *nobody directly in your life, in your house. I think just that moral and physical support*  
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23 478 *there is a help, every little helps, it's only a small percentage, it's a definite help"* (Patient  
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### 31 481 **Time**

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34 482 Participants' accounts and descriptions of attempts to adapt to UC since diagnosis demonstrate  
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36 483 that this is an iterative and ongoing process of trial and error. People test the boundaries of  
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38 484 abilities and the role of adaptation methods and may take time to gain the necessary  
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40 485 facilitators to adaptation, and also to reach a point of acceptance of the disease or not.  
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42 486 Similarly, the role of medical therapies in improving physical wellbeing is often reported as  
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44 487 being tested iteratively over time in collaboration with healthcare professionals. Finally,  
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46 488 circumstances may change over time, such as the frequency and severity of flares.  
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### 52 490 **DISCUSSION**

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3 491 To our knowledge, this is the first paper in UC and the IBD sphere to propose a framework of  
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6 492 normality (Figure 1) to categorise and understand patients' overall experience of life with the  
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9 493 disease, and the factors that influence adaptation to it. The concept of disease-related  
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11 494 normality helps us to think about how disease impacts on patients holistically; the interplay of  
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13 495 physical symptoms; the consequences for daily life; and how patients see themselves and their  
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16 496 lives as a result. It shows how disease can be a disrupting life experience (the 'non-normal  
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18 497 life'), and how patients approach adaptation and whether, broadly speaking, they are  
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21 498 successful in this (the 'normal-life'). In the absence of cure, disease symptoms, adaptation  
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23 499 strategies and outside support cumulate to influence patients' views on life with the disease.  
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26 500 This can change over time, with acceptance of the disease and need to adapt, and with  
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28 501 changing circumstances, such as treatment, disease progression and the presence or absence of  
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31 502 outside support.

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36 504 For patients with UC to be able to live a 'normal life', traditional medical management is likely  
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38 505 to be important but as highlighted in this sample, may be insufficient on its own. The majority  
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41 506 of patients described other adaptation methods that they felt were required, that they had  
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44 507 tried and tested, or were in the process of testing. These methods aimed to achieve different  
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46 508 but interrelated things; physical and psychological wellbeing; the ability to carry on working and  
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49 509 to prevent embarrassment. There may not be good evidence that the aims of the adaptation  
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51 510 strategies can be achieved by the specific methods adopted by patients. As we have described,  
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54 511 patients themselves often actively reflect on the efficacy of their actions, for example, in  
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56 512 monitoring and adjusting diet to influence physical wellbeing. Despite this, the trial and error  
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3 513 adoption of different strategies may in itself be important as part of a process of  
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6 514 accommodating disease and being active in doing so. Research in diabetes<sup>29</sup> has proposed that  
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9 515 such actions are important for young people in attempting to 'master' their disease, and recent  
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11 516 research around normality in cancer survivorship<sup>30</sup> has also indicated that the act of doing  
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13 517 things is important in its own right regardless of the outcome of the action itself.  
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18 519 It was also clear that adaptation and normality were specific to the individual, meaning  
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21 520 different things to different people. Re-formulating identity and sense of self with disease is  
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23 521 crucial for adaptation. Loss of sense of self has been identified as integral to chronic disease  
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25 522 experience generally,<sup>31</sup> and other researchers interested in normality in IBD have also observed  
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27 523 that identity influences views on normality.<sup>9,15,17</sup> For a normal life to be achieved, the disease  
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29 524 and its impacts have to be accommodated via adaptation, and thereby integrated into a new,  
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31 525 and perhaps dynamic, sense of self. We did not talk to anyone with UC who described their life  
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33 526 as being the same as before the onset of disease. However, for many, the physical burden of  
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35 527 disease will preclude this adaptation and for others there may be a significant period of time  
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37 528 before adaptation is achieved.  
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46 530 The in-depth participant-focused qualitative research approach used here has allowed us to  
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48 531 gather and analyse rich and detailed accounts of patients' perspectives on living with and  
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50 532 adapting to UC. We have talked to a range of patients who have lived with UC for varying  
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52 533 periods of time. There are however limitations to our approach. All of the patients interviewed  
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54 534 were participating in a pilot trial and as such the range of patients was influenced by the trial  
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3 535 eligibility criteria. This meant for example that everybody was in remission at the time of the  
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6 536 interview. Those with longstanding mild and controlled disease were less likely to figure in this  
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9 537 research as patients had to have had a relapse within the 12 months preceding recruitment.  
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11 538 However, these are potentially the patients most likely to be able to adapt. Additionally this  
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13 539 research is cross-sectional in nature and so we have not been able to observe the temporal  
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16 540 components of adaptation over time, although we have interviewed patients who have been  
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19 541 diagnosed with UC between 1 and 22 years. Further research with a broader range of patients  
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21 542 and perhaps with a longitudinal design may provide further insight.  
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26 544 Several patients commented that they had welcomed the opportunity to talk about their views  
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28 545 in-depth to someone outside of the clinical team. A few of them said that they felt that their  
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31 546 clinicians were not always receptive to the broader context that they were able to talk about as  
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33 547 participants in this research. The implications of this for clinical practice need to be explored  
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36 548 further. Naturally, clinicians may focus on the physical and clinical manifestation of disease. As  
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38 549 described here, physical wellbeing is a core component of adaptation and a 'normal life'.

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41 550 However, physical disease and its impacts are experienced holistically by patients and those  
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44 551 around them. The efficacy of medical and surgical management and patients' relationship to  
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46 552 this e.g. via adherence, shared decision-making re treatment options, and interactions with  
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49 553 healthcare professionals and services, will be judged by patients within the broader context of  
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51 554 adaptation that we have described here. Other authors have recently reflected on the need to  
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54 555 identify and address poor adaptation to IBD as a means to impact on quality of life and also  
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56 556 potentially the course of disease.<sup>32</sup> The consideration and development of interventions that  
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3 557 facilitate adaptation and self-management in UC may help to reflect the holistic experience and  
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6 558 priorities of UC patients.  
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## 10 560 **CONCLUSION**

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13 561 In this study, we have described the views of patients, who for the most part did not use  
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16 562 biologics, on the factors that influence their adaptation to UC and whether they perceived that  
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18 563 they are able to regain and maintain a 'normal life'. We have shown that adaptation to UC is  
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21 564 complex and that medication alone is most often insufficient to achieve this. Symptoms,  
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23 565 adaptation strategies and outside support all have an influence on whether patients manage to  
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26 566 regain and maintain normality over time. This holistic view of adaptation to UC will help  
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28 567 clinicians and researchers to understand patients' views on life with the disease and the role of  
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31 568 medical and other therapies within this.  
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53 577 Alison Moore, Lisa Richardson, and Julie Reddan.  
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3 579 **Contributions**  
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5  
6 580 All authors made a substantial contribution to the manuscript. JM designed and conceived the  
7  
8 581 qualitative research with TP. CM (Research Fellow) conducted the interviews. Data analysis was  
9  
10 582 carried out by CM, JM and LJ, and interpretations checked with all authors. The manuscript was  
11  
12 583 drafted jointly by CM and JM. All authors revised the manuscript for intellectual content. All  
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15 584 authors have read and approved the final manuscript.  
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21 586 **Patient consent**  
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23 587 Obtained.  
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28 589 **Data sharing statement**  
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31 590 No additional data are available.  
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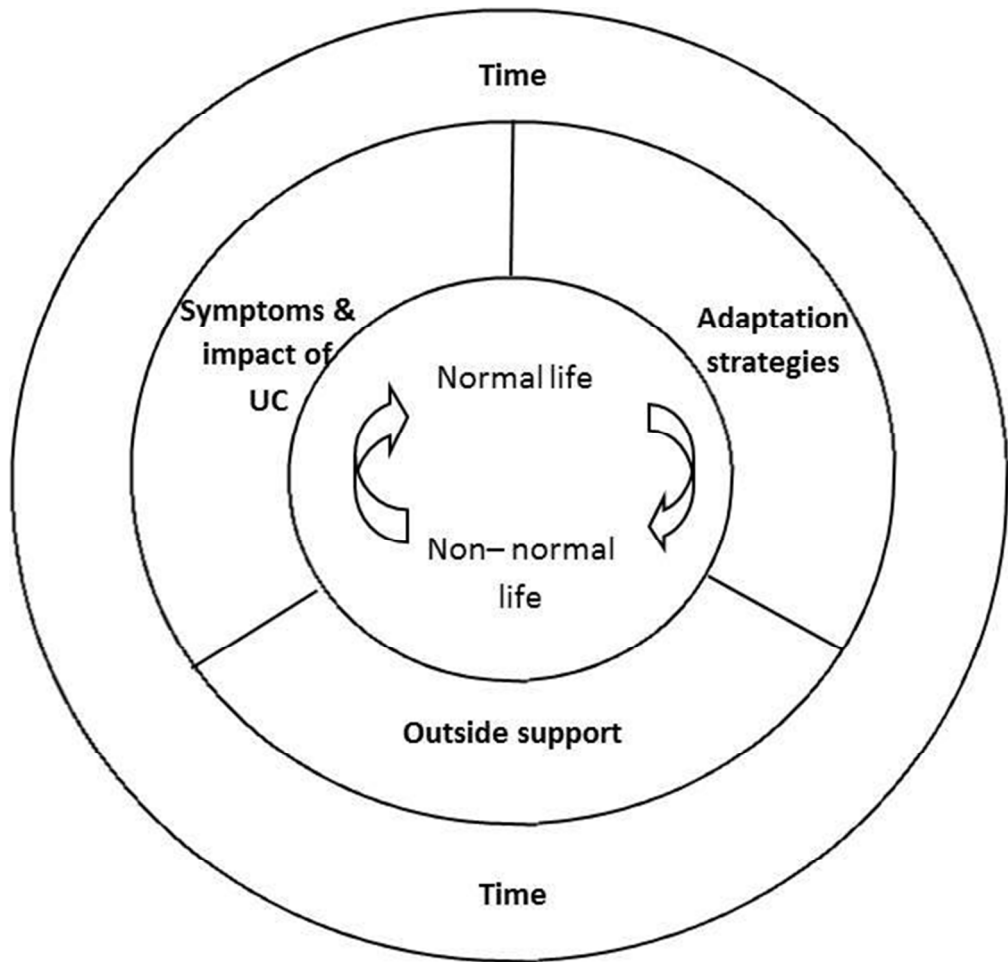
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6 674 **FIGURE LEGEND**  
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8 675 Figure 1 – Influences on normality in ulcerative colitis  
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**FIGURE LEGEND**

Figure 1 – Influences on normality in ulcerative colitis

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Influences on normality in ulcerative colitis

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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**