

# 1 Exploring adult critical illness survivors' experiences of fatigue: A qualitative study

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## 5 ABSTRACT

6 **Aims:** To explore adult experiences of fatigue after discharge from an intensive care unit and to identify  
7 potential management strategies.

8 **Design:** An exploratory qualitative study

9 **Methods:** One to one audio-recorded semi-structured interviews with 17 adult survivors of critical  
10 illness in the United Kingdom, lasting up to one hour, between September 2019 and January 2020.  
11 Anonymised and verbatim-transcribed interview data underwent a standard process of inductive  
12 thematic analysis as described by Braun and Clarke.

13 **Findings:** Three themes were identified: fatigue is different for everyone; complex interrelating  
14 interactions; and personalised fatigue strategies. Fatigue was described as a distressing symptom,  
15 unique to the individual that causes an array of complex, often long-term interrelating impacts on the  
16 survivor and their wider family, made worse by a lack of understanding, empathy, and support  
17 resources. Support from others, alongside interventions such as exercise, good nutrition, information,  
18 and alternative therapies are used by survivors with variable degrees of success.

19 **Conclusions:** This qualitative study reports peoples' experiences of fatigue after critical illness. Findings  
20 highlight the significant impact it has on people's lives and those of their family and friends.

### 21 **Impact: aim; findings and recommendations**

- 22 • This study explored the problem of fatigue in survivors of critical illness.
- 23 • Fatigue causes an array of complex, often long-term interrelating impacts on the survivor and  
24 their wider family, made worse by a lack of understanding, empathy, and support resources.  
25 Interventions such as exercise, good nutrition, information and alternative therapies are used by  
26 survivors with variable degrees of success.
- 27 • Acknowledgement of fatigue by health and social care staff and the provision of personalised  
28 information to patients and their family on fatigue and how it can be managed could improve  
29 patients' experience and their overall quality of life.

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31 **Key words:** qualitative research; critical illness; rehabilitation; fatigue; nursing

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## 34 INTRODUCTION

35 Improving the long-term health outcomes of survivors of critical illness is an international research  
36 priority (Latronico et al., 2017; Reay et al., 2014) and aligns with the aims of the United Kingdom (UK)  
37 National Health Service (NHS) long term plan (NHSEI, 2019). Prior to the COVID-19 pandemic,  
38 approximately 86% of patients admitted to an intensive care unit (ICU) survived, equating to  
39 approximately 139,148 people per annum within the UK (ICNARC, 2020). In the United States, 4.85  
40 million people survive critical illness to hospital discharge (Daniels et al., 2018). Due to COVID-19, ICU  
41 admissions across the globe have substantially increased. In December 2020, in the UK, there were  
42 3,340 people in ICU compared with 2,512 in December 2019 (Public Health England, 2021).

43 This paper reports a qualitative study examining survivors' experiences of fatigue, a symptom  
44 experienced by up to 80% of people after ICU discharge (Bench et al., 2021). Qualitative inquiry is  
45 imperative to support the development of interventions that can successfully mitigate fatigue; for  
46 people recovering after COVID-19 as well as those with other conditions causing critical illness.

## 47 Background

48 Post intensive care syndrome (PICS) is a constellation of long lasting physical, psychosocial, and cognitive  
49 impairments experienced by up to half of people after a critical illness (Kosinki et al., 2020). PICS can  
50 persist for several years after hospital discharge, negatively affect quality of life (Daniels et al., 2018;  
51 Hashem et al., 2016; van Beusekom et al., 2018) and delaying or preventing a return to previous social,  
52 personal, and work-related roles. Health and social care utilisation can also be high, because of the need  
53 for long-term multi-professional care (Griffiths et al., 2013; Kamdar et al., 2020). Fatigue is one of the  
54 numerous symptoms associated with PICS (Bench et al., 2021; Cajanding et al., 2017; Souron et al.,  
55 2021). Other symptoms include anxiety, depression, post-traumatic stress disorder, sleep dysfunction,  
56 concentration difficulties, memory deficits and problems with mobility and breathing.

57 Fatigue is described as an overwhelming, sustained sense of exhaustion, typically unrelieved by sleep,  
58 with decreased capacity for physical and mental work at a usual level (Herdman and Kamitsuru, 2014).  
59 Fatigue is multidimensional in nature (Cajanding et al., 2017) but its aetiology is poorly understood. It is  
60 associated with many pathological conditions, including both neurological and non-neurological diseases  
61 (Spadaro et al., 2016). In addition to the medical diagnosis leading to an ICU admission and an  
62 individual's co-morbidities, several other factors contribute to fatigue in critically ill patients. These  
63 include pain (Boyle et al., 2004; Choi et al., 2014a), weakness, anaemia, poor nutrition, anxiety,  
64 depression, sleep disturbances and other common environmental and situational factors such as  
65 abnormal light, noise and temperature, which are experienced by people whilst in ICU and during  
66 recovery (Bench et al., 2021; Matthews, 2011; Souron et al., 2021). Medications administered in ICU  
67 may further aggravate fatigue due to their effects on a person's mood, conscious level, mobility and/or  
68 homeostatic mechanisms (Zlott and Byrne, 2010). For example, steroids, sedatives, and muscle relaxants  
69 are associated with ICU acquired weakness (Friedrich et al., 2015), which can persist for several years  
70 after discharge (John and Bapat, 2015).

71 A mixed methods systematic review of the literature by Bench et al. (2021) concluded that fatigue is  
72 evident in up to 80% of survivors, predominantly measured using SF-36 vitality scores as a surrogate  
73 marker. Fatigue is particularly common in the early period after ICU discharge. One German cohort  
74 study by Wintermann et al. (2018) noted that nearly every second patient discharged after a minimum  
75 of six days stay in ICU had clinically relevant fatigue symptoms at 3- and 6-months post discharge.  
76 However, a study by Spadaro et al. (2016) and a narrative review of the broader population by Souron et  
77 al. (2021) also report data showing that fatigue can be present many years later in some survivors.

78 Numerous studies and systematic reviews report data on PICS and its spectrum of symptoms (for  
79 example, Lee et al., 2020; Ohtake et al., 2018), but research specifically exploring people's experiences  
80 of fatigue and its impact on their lives is rare. The systematic review by Bench et al. (2021) located only  
81 one small-scale study reporting qualitative data focusing on fatigue, published as a conference abstract,  
82 with full text made available by the authors (Colman et al., 2015). This Australian mixed methods study  
83 used phenomenology to explore the experiences of fatigue in survivors of critical illness a year or more  
84 post ICU discharge. Participants (n=5) described physical and cognitive dysfunction that worsened with  
85 increased fatigue and discussed how it negatively altered their parental, worker, spousal and social  
86 roles. The other eight qualitative or mixed methods studies included in this review (Ågård et al., 2012;  
87 Choi et al., 2014a; Eakin et al., 2017; Elliott et al., 2019; Kang and Jeong, 2018; König et al., 2019; Maley  
88 et al., 2016; Strahan et al., 2005) and other qualitative reviews (Hashem et al., 2016) discuss fatigue at  
89 different points in the recovery period, only as part of a wider focus on health-related quality of life after  
90 critical illness. Further qualitative research exploring patients' experience is needed to underpin the  
91 development of fatigue focused interventions.

## 92 **THE STUDY**

### 93 **Aims**

94 The aim of this study was to explore adult experiences of critical illness related fatigue. The research  
95 questions were:

- 96 1. How do adult critical illness survivors experience fatigue?
- 97 2. How does fatigue affect individuals' lives?
- 98 3. What factors do survivors associate with the presence and severity of fatigue?
- 99 4. What strategies do survivors use to mitigate their fatigue and to what extent are they  
100 successful?

101 This study is reported in line with the consolidated criteria for reporting qualitative research (COREQ) 32  
102 item checklist, broken into three key domains: Research team and reflexivity; Study design; Analysis and  
103 findings (Tong et al., 2007).

### 104 **Design**

105 This study, seeking peoples' experiences, employed a qualitative methodology. A qualitative research  
106 approach, which generates knowledge grounded in human experience, (Sandelowski, 2004) was  
107 imperative to gaining an in depth understanding of fatigue. This exploratory study was informed by

108 interpretivism. The goal of interpretivism is to understand and find meaning in experiences from  
109 multiple subjective perspectives (Welford et al., 2011). As such theory may emerge inductively.

## 110 **Sample/Participants**

111 We recruited a purposive sample of adult survivors of critical illness who experienced fatigue after  
112 discharge from an ICU in the UK. We agreed a maximum variation sampling approach based on age, sex,  
113 admitting diagnosis, length of stay and time since critical illness.

### 114 ***Inclusion criteria***

- 115 • Adult (>18 years) survivors of critical illness
- 116 • Current or previous experience of fatigue after ICU discharge

### 117 ***Exclusion criteria***

- 118 • Not yet discharged from hospital
- 119 • Lack of capacity
- 120 • Unable to speak or understand English.

121

122 Participants were recruited via an advert circulated on Twitter (supplementary file 1). We also asked  
123 professional colleagues to distribute study information amongst their networks. We did not offer any  
124 incentives for participation. Those who registered interest were sent study information via email.

## 125 **Data collection**

126 One to one audio-recorded semi structured interviews, lasting up to one hour, were conducted between  
127 September 2019 and January 2020. Interviews took place by telephone, to ensure geographical location  
128 was not a barrier to participation (Sturges and Hanrahan, 2004).

129 An interview topic guide informed by the literature was designed by the project team (supplementary  
130 file 2). Questions were piloted in the first interview and no amendments were deemed necessary.  
131 Participants were asked open questions, divided into three sections: experiences of critical illness;  
132 impact of fatigue; mitigating factors. Participants were given opportunity to add other information they  
133 felt relevant and to ask any questions before the close of the interview. Limited new information  
134 emerged after the first 15 interviews, and we considered data saturation likely to have occurred after 17  
135 interviews.

136 Notes on factors influencing the interview or key issues that arose were made by the interviewers and  
137 added to the interview transcripts. Transcripts were not returned to participants as there is little  
138 evidence that this improves research credibility (Thomas, 2017).

## 139 **Ethical considerations**

140 The study received university ethical approval (ETH1819-0106). Discussing critical illness experiences can  
141 be traumatic. Two experienced qualitative researchers, both of whom are registered critical care nurses

142 (XXX) conducted all interviews, so appropriate support and signposting to support services such as the  
 143 ICUsteps Charity (<https://icusteps.org/>) could be offered if necessary.

#### 144 **Data analysis**

145 Anonymised and verbatim-transcribed interview data were uploaded into NVivo<sup>12</sup> and underwent a  
 146 standard process of inductive thematic analysis, using coding to identify recurring patterns and collating  
 147 these into key themes (Braun and Clarke, 2005). The primary purpose was to attain descriptive data  
 148 about people's experiences of fatigue, its impact on their lives and strategies they use to mitigate its  
 149 impact. The research assistant first coded all transcripts, which were reviewed by the qualitative  
 150 researchers (XXX) and used to produce draft themes. A consensus approach amongst the project team  
 151 resolved any differences in interpretation prior to agreeing final themes.

#### 152 **Rigour: Research team and reflexivity**

153 Led by a Professor in critical care nursing (XX), this study was conducted by a multi-professional team of  
 154 females (n=3) and males (n=1) from four UK Universities, including critical care nursing (XXX) and  
 155 medical (XX) clinical academics, an expert qualitative researcher in fatigue (XX) and a trainee  
 156 psychologist acting as a research assistant (XX). Interviews were performed by experienced qualitative  
 157 researchers (XXX), both critical care nurses, however, no participants were known to the research team.  
 158 To account for researcher influences on the data, a reflexive diary was kept by research team members.  
 159 All decisions regarding data collection and analysis were discussed and agreed by the whole team and a  
 160 written record kept demonstrating transparency, truth, consistency, confirmability, and applicability  
 161 (Noble and Smith, 2015).

#### 162 **FINDINGS**

163 Seventeen of the 34 people who registered interest were included in the study. Key reasons for not  
 164 taking part included:

- 165 • Did not meet the inclusion criteria as not based in UK or had not been in an ICU (n=11)
- 166 • Family emergency (n=1)
- 167 • Lost to follow up (n=5)

168 The 17 study participants included 11 females and six males, predominantly white British, ranging in age  
 169 from 28 to 63 years (see table 1).

170 Table 1: Sample characteristics

171 Table 2 details the initial codes that emerged from the interview data, which informed the development  
 172 of the three overarching themes: (i) fatigue is different for everyone; (ii) complex interrelating  
 173 interactions; and (iii) personalised fatigue strategies.

174 Table 2: Themes, subthemes and codes

#### 175 **Fatigue is different for everyone**

176 Study participants described fatigue in multiple ways. Some struggled to explain it: *“I can’t really*  
 177 *describe it, it was heavy, there’s a horrible monkey on your back kind of thing”* (P9, female, age 51).  
 178 However, participants emphasised how different it was from tiredness.

179 For some people, fatigue was a predominantly physical experience. One participant explained: *“It’s like*  
 180 *you’ve been poured with concrete and it was just setting slowly from the feet up...it literally felt like the*  
 181 *concrete was hardening and everything was stopping”* (P2, female, age 37). Another described: *“feeling*  
 182 *like you’re walking through treacle”* (P8, male, age 55). In contrast, others expressed it as a sort of a  
 183 mind exhaustion: *“just a complete brain fog”* (P5, female, age 32) or like a computer virus: *“A bit like in*  
 184 *the old days when we first had PC’s and they got a virus. Your brain just kind of shuts down”* (P14, male,  
 185 age 61). Many participants described a combination of these feelings.

186 In some cases, fatigue was present from the start of recovery, whereas in others it came on gradually.  
 187 Similarly, whereas for some it improved over time, others were still experiencing fatigue many months  
 188 and sometimes years after hospital discharge. This was unexpected, as explained by one man: *“If you’d*  
 189 *said to me...you know, in a years’ time I’d still be fatigued and I’d still be expecting maybe 12/14 hours a*  
 190 *day in bed I would have said, just put me back under and leave me”* (P15, male, age 53).

191 Fatigue could also be unpredictable, which left people feeling out of control. One participant explained  
 192 how she would be out shopping and be completely alright only to be met with an urgency to sit down:  
 193 *“I’d think oh I’m going to be fine and I’m holding on the trolley right obviously and I’ll say to my husband,*  
 194 *I have to sit down, I have to sit down right now”* (P13, female, age 65). Others described experiencing  
 195 fatigue in a cyclical pattern: *“...it comes in cycles...I’ve had that happen a couple of times, that I’ve felt*  
 196 *brighter and better, and then I’ve just felt really weary again”* (P10, female, age 68).

### 197 **Complex interrelating interactions**

198 Participants described the significant impact that fatigue had on the whole of their lives; physically,  
 199 socially, cognitively and emotionally, aspects that had a complex interaction.

200 Participants talked about how fatigue affected them physically on a day-to day basis. One lady said: *“Just*  
 201 *opening my eyelids, that was tough, or even lifting up my arm to pull back the covers to get out of bed,*  
 202 *just could not manage it”* (P12, female, age 63), whilst another explained: *“It was as if I was about to*  
 203 *drop. I literally had no energy. I had to lie down. I had to lie down...if I was outside in the street honestly,*  
 204 *I could have seen myself lying down on the pavement”* (P17, female, age 58). Others described a state of  
 205 permanent exhaustion associated with long-term sleeping difficulties. Carrying out simple tasks left  
 206 some people so fatigued they would have to rest for long hours the following day as one participant  
 207 illustrated: *“Getting dressed in the morning would send me back to bed for two hours”* (P8, male, age  
 208 55).

209 Fatigue also affected the wider family as people struggled to engage in their normal roles as parents,  
 210 partners, or children. Family members often took on additional care and support roles. One participant  
 211 said: *“We had to kind of rearrange our whole lives really, my husband changed hours to make sure that*  
 212 *he was home to do things because I couldn’t stand there and iron my son’s school uniform, I didn’t have*

213 *the energy to stand up and do it*" (P2, female, age 37). Another participant described the impact on his  
 214 partner, saying: *"My husband, yeah obviously he had to do so much...he sort of had to take over*  
 215 *everything at home when I was just sitting and would fall asleep on the sofa and could not do anything.*  
 216 *So yeah, it was difficult for him"* (P16, male, age 54).

217 Fatigue meant that some people could not socialise in the same way they had prior to their critical  
 218 illness. As one participant said: *"I'm just too tired... I don't want to put myself out...I don't really want to*  
 219 *engage too much"* (P12, female, age 63). Another participant explained: *"I'm not keen to go to the*  
 220 *cinema or the theatre, both of which I thoroughly enjoy. Because it just becomes a late night and that's*  
 221 *one of the things that triggers the fatigue"* (P14, male, age 61). Even spending time with friends was  
 222 challenging as having to concentrate on conversations added to the mental fatigue: *"I have tried to go*  
 223 *out with my friends...But I do find it very, very exhausting but they understand that I just have to say I'm*  
 224 *going to go home now, I can't do it anymore"* (P3, female, age 65). Participants used terms such as "anti-  
 225 social" to describe their life post critical illness, with some finding it easier not to engage at all.

226 Fatigue affected people's ability to work and, in some cases, caused financial difficulties. One participant  
 227 described how work left him exhausted: *"I think the physical effort of going to work definitely but also*  
 228 *the mental effort of work...I was shattered at the end of the day, absolutely shattered"* (P16, male, age  
 229 54). Another participant explained: *"Thinking things through...is what gives me fatigue...sitting down and*  
 230 *thinking how are we going to do it...will just fatigue me"* (P14, male, age 61). For some, work just wasn't  
 231 an option: *"I tried to go back to work very gradually. And did that for about a month and a half and then*  
 232 *I realised I couldn't because I was just too fatigued"* (P16, male, age 54).

233 Fatigue also affected people's minds in different ways. For one participant, fatigue meant she struggled  
 234 to retain information and needed to set herself reminders: *"I struggle with concentration...I write the*  
 235 *letter of the day on [tablet holder] because I take it and five minutes later, I've forgotten if I've taken it"*  
 236 (P5, female, age 32). Participants also talked about how difficult it was to read and write. One  
 237 participant said: *"I just really struggle to take the information in... if I'm reading a book, I can read as*  
 238 *little as one page of an A5 book and my brain just goes... pffft!"* (P5, female, age 32). Another participant  
 239 explained: *"My head would say, ball and my pen would write something else and then I'd read back this*  
 240 *sentence and it made no sense at all, it was really bizarre and that went on for ages"* (P13, female, age  
 241 65). One participant described the challenge of simply making a cup of tea: *"I was just so tired, even*  
 242 *putting two sugars in my tea, had to think have I put one or two sugars in my tea? No, I'm so tired. I*  
 243 *can't even think straight"* (P17, female, age 58).

244 Participants described feeling frustrated with people's lack of understanding and feeling lonely as a  
 245 result: *"The lack of understanding both in your closer circles and in the medical profession means that*  
 246 *there is a loneliness that comes on which I think does affect you mentally"* (P1, female, age 28). One  
 247 participant explained the emotional impact this lack of understanding from her friends had on her:  
 248 *"They joke about it...I just joke back but it does hurt...I feel ashamed. I feel embarrassed and I hate it"*  
 249 (P5, female, age 32).

250 Participants also described examples of how the actions and attitudes of healthcare staff were  
 251 unhelpful. One participant explained she felt: *“People were dismissive of it especially the Doctor...I felt*  
 252 *like I was wasting his time so I got to the point where I just stopped even saying anything...I just stopped*  
 253 *even mentioning it because I felt quite stupid.”* (P2, female, age 37). For some, this made them feel  
 254 ‘abnormal’ and led to other symptoms including anxiety and depression.

### 255 **Personalised fatigue strategies**

256 Participants described a range of ways they tried to manage their fatigue. Exercise, including things such  
 257 as swimming, running, walking or gardening often helped. One participant explained how going outside  
 258 to exercise improved his overall mood and made him feel more positive: *“The psychological things*  
 259 *around exercise being outside, the endorphins released while you exercise, the feeling of accomplishing*  
 260 *something”* (P16, male, age 54). In contrast, others needed increased rest to manage their fatigue,  
 261 although participants pointed out that sleeping did not always make the fatigue better.

262 The importance of pacing activities and doing one thing at a time was emphasised: *“I have to think*  
 263 *about everything from just going up the staircase or just brushing my teeth...I just try and take my time*  
 264 *and not rush things”* (P7, male, age 60). Others commented on how eating and sleeping well, and  
 265 incorporating things like hypnosis, meditation, reflexology or other alternative therapies into their life,  
 266 helped their overall wellbeing: *“Craniosacral therapy, that has had probably the most astounding effect,*  
 267 *probably more so than reflexology... I really don’t know how to explain it, it’s like magic!”* (P9, female,  
 268 age 51).

269 Participants described how they tried to find things that motivated them, such as walking the dog or  
 270 setting themselves a goal. In many cases, family members were crucial to helping people manage their  
 271 fatigue. For example, one participant explained how the family support gave her the time to rest: *“The*  
 272 *two boys are very good at doing the washing up and my husband...he does this full time, full on job, and*  
 273 *then he comes back and starts doing the washing and cooking tea and things”* (P11, female, age 50).  
 274 Another participant had returned to live with her mum because: *“knowing that there’s somebody else in*  
 275 *the house means that I can sleep in in the morning”* (P5, female, age 32).

276 Participants further described the value of physiotherapy, occupational therapy, psychology, a good  
 277 general practitioner, and other community-based support. Participants often chose to spend time with  
 278 people they felt understood their fatigue and valued meeting others who had experienced fatigue. One  
 279 participant explained: *“I’m thankful that I have very good, close friends. They’re a nice handful of people*  
 280 *but they understand completely. Many of the others didn’t at all”* (P8, male, age 55). Another said: *“I*  
 281 *was just kind of choosey on what I did and who I did it with, you know, the people that knew me before*  
 282 *maybe wouldn’t understand”* (P6, male, age 32).

283 For some people, nothing at all helped their fatigue. As one participant explained, *“I just feel like it’s in*  
 284 *the lap of the gods”* (P1, female, age 28). People had tried several things unsuccessfully. One participant  
 285 said: *“I thought that if I watched TV, I might be able to keep my eyes open and be engaged with the*  
 286 *world...I would hear the first few words of a sentence and I couldn’t be bothered because I would just fall*  
 287 *asleep, and I never got to the end of the news section [laugh]”* (P12, female, age 63). Despite its



288 potential benefits, exercise also proved difficult for some as highlighted by one participant: *“I would do*  
 289 *five lengths [swimming] and I would struggle getting out of the pool”* (P2, female, age 37). In addition,  
 290 some aspects of life were not necessarily modifiable. For example, one participant discussed how her  
 291 age, sex and bodily changes seemed to worsen her fatigue: *“Sometimes I think it’s things like hormones*  
 292 *and, you know, I’m going through the menopause and it could be that”* (P11, female, age 50).

293 The need to be listened to, and for information, empathy and support was emphasised. As one  
 294 participant said: *“If they’d [medical staff] explained it better to me...I think if they could just give you*  
 295 *more information or even tell you this is what you might feel like”* (P3, female, age 65). Participants who  
 296 did receive information felt it helped them to accept fatigue as a normal part of the recovery process.  
 297 Participants also highlighted the importance of giving information about fatigue to partners, friends and  
 298 children. The overwhelming message from participants, highlighted in this quote was that: *“You*  
 299 *definitely need some support somewhere and [need] to be kind to yourself and to give yourself time”* (P4,  
 300 female, age 33).

## 301 **DISCUSSION**

302 Fatigue is a distressing symptom for many ICU survivors and has been ranked by patients as one of the  
 303 most important outcomes post critical illness (Nedergaard et al., 2018). The impact fatigue has on  
 304 people’s lives has been brought into focus during the COVID-19 pandemic (Carfi et al., 2020). Our  
 305 qualitative findings show how each person’s experience of fatigue is unique and highlight that fatigue is  
 306 not the same as everyday tiredness.

307 Our findings build on the limited qualitative research evidence highlighting how fatigue creates a set of  
 308 complex interrelating problems that is rarely acknowledged. Our data also highlight the impact of  
 309 fatigue on the wider family unit, previously reported by Celik et al. (2016), Choi et al. (2014b) and Day et  
 310 al. (2013). Reliance on others was a concern expressed in our data, particularly for those who lived alone  
 311 and did not have easy access to help and support. The level of community-based support available  
 312 varies enormously, impacting people’s experiences and their rehabilitation progress; a problem  
 313 experienced more widely for critical illness survivors (King et al., 2019).

314 We recruited our sample via social media and using our own professional networks, as opposed to more  
 315 traditional approaches. This gave people not directly connected to health and social care services  
 316 opportunity to participate; however, it did result in a broad sample representing a range of different  
 317 critical illness and timelines. The mean age of our sample was 50.76 years (SD 12.81), younger than that  
 318 reported by Spadaro et al. (2016) (median 67.5, IQR 59-74). Length of ICU stay (25.2 days, SD 20.94,  
 319 range 3-84) was also much longer than the 10 ± 11 days reported by Spadaro et al. (2016) and the 14 ±  
 320 11 days reported by Neufeld et al. (2020) in their study focusing on ARDS patients. These differences  
 321 may have impacted on people’s reported experiences. All participants were, however, still experiencing  
 322 fatigue, despite some having been discharged from hospital for over eight years. These findings highlight  
 323 the need to develop assessment tools that help patients communicate their experiences of fatigue and  
 324 its impact on their life.

325 Implications for future practice

326 The results of a systematic review by Lee et al. (2020) suggest that to prevent PICS, the multidisciplinary  
327 team should pay attention to the patient experience. Fatigue is only one of many symptoms associated  
328 with PICS and it can be difficult to untangle its stand-alone effects, however, the experiences described  
329 by our participants suggest that fatigue underpins many of the wider problems associated with PICS.

330 Our findings emphasise the need for a personalised approach to managing fatigue as what makes one  
331 person feel better might make another feel worse or be of no benefit whatsoever. Our qualitative data  
332 should inform the development and evaluation of future interventions, based on patients' experiences  
333 of fatigue and their expressed support needs. Our findings support those from studies with other  
334 population groups, which suggest that there are a range of potentially modifiable factors, which if  
335 targeted in a positive way, could help reduce the impact of fatigue (Artom et al., 2016). Our findings also  
336 support recommendations from a narrative review by Souron et al. (2021) and editorials by Hosey et al.  
337 (2021) and Spadaro (2020) that tailored interventions targeting individual needs are required.

338 Interventions identified as useful by our participants include support from others, exercise (particularly  
339 swimming or being outside), alternative therapies (such as meditation), good nutrition, information and  
340 help setting achievable goals. These interventions have already proved effective for managing fatigue in  
341 those with, for example, cancer, kidney failure and inflammatory bowel disease (Baguley et al., 2017;  
342 Czuber-Dochan et al., 2013; Meneses-Echávez et al., 2015; McCann, 2016; Tao et al., 2015). To date, no  
343 published study has tested these interventions in the critical care population (Bench et al., 2021),  
344 although an ongoing systematic review is examining non-pharmacological strategies for improving  
345 health outcomes after critical illness, including fatigue (Geense et al., 2017).

346 Educating health and social care professionals and providing information to patients and their families  
347 improves people's experiences, positively impacting their overall quality of life (Bench et al., 2015;  
348 Bench et al., 2016). Currently available information, for example, the ICUsteps website ([Guide to  
349 intensive care - ICUsteps](#)), the critical care recovery website ([Critical Care Recovery](#)) and resources  
350 offered by the intensive care society ([Resources | Patients and relatives \(ics.ac.uk\)](#)) could be further  
351 developed to better explain fatigue and its management. Our findings suggest that information  
352 resources should describe what fatigue might feel like, highlight its uniqueness to the individual, include  
353 potential reasons for fatigue, offer advice on what the patient and their family can do themselves and  
354 signpost people to appropriate support.

355 Opportunities to discuss fatigue with patients should also be taken as early as possible by all members of  
356 the healthcare team. It is also vital that community-based personnel understand about fatigue as well as  
357 other potential critical illness sequelae (Bench et al., 2016). Hosey et al. (2021) point out, however, that  
358 information and education alone is not enough and needs to be coupled with active management,  
359 focused on the thoughts, behaviours and complications that limit recovery. This includes the attitude  
360 and behaviour of others, as these are an important determinant of how people with fatigue feel about  
361 themselves. Our findings highlight how a general lack of understanding and empathy around fatigue can  
362 leave people feeling 'abnormal' and can trigger other common PICS symptoms such as post-traumatic  
363 stress disorder, anxiety and depression (Righy et al., 2019).

## 364 **Limitations**

365 We did not meet our target sample of 20 and did not therefore achieve our goal of maximum variation  
366 sampling. Due to the start of the COVID-19 pandemic, we did not pursue further data collection. Some  
367 of our participants had other conditions that can cause fatigue, such as cancer, anaemia, and kidney  
368 failure or were taking medications, for example, analgesics, known to cause fatigue. Furthermore, we  
369 did not collect data about the length of time our participants received mechanical ventilation, which  
370 could have been an important variable affecting people's experiences. Neither did we collect data about  
371 pre-ICU fatigue level. This made it difficult at times, to untangle the extent of the fatigue caused by the  
372 critical illness.

373 Despite these limitations, we are confident that our findings reflect people's experiences of fatigue after  
374 critical illness. Many participants had no other precipitating causes, and our findings are congruent with  
375 other research findings, although our study sample reflects only the pre-COVID-19 ICU population. The  
376 robust data analysis process undertaken by the research team further strengthens our conclusions.

## 377 **CONCLUSION**

378 This study explored adult experiences of critical illness related fatigue and identified strategies people  
379 have used to mitigate their fatigue. This is the first qualitative study undertaken in the UK reporting  
380 peoples' experiences of fatigue after critical illness. Fatigue is a distressing symptom, unique to the  
381 individual that causes an array of complex, often long-term interrelating impacts on the survivor and  
382 their wider family, made worse by a lack of understanding, empathy, and support. Acknowledgement of  
383 fatigue by healthcare staff and providing information about how fatigue can be mitigated could improve  
384 people's experiences post critical illness and their overall quality of life.

## 385 **Conflict of Interest statement**

386 XX is a National Institute for Health Research (NIHR) 70@70 Senior Nurse and Midwifery Research  
387 Leader. XX is currently supported by an NIHR Doctoral Research Fellowship (XXX). The views expressed  
388 in this article are those of the authors and not necessarily those of the NIHR, or the Department of  
389 Health and Social Care in England.

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