**ABSTRACT**

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

**Design:** An exploratory qualitative study

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

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

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

**Impact: aim; findings and recommendations**

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

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

**INTRODUCTION**

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

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

**Background**

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

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

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

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

**THE STUDY**

**Aims**

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

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

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

**Design**

This study, seeking peoples’ experiences, employed a qualitative methodology. A qualitative research approach, which generates knowledge grounded in human experience, (Sandelowski, 2004) was imperative to gaining an in depth understanding of fatigue. This exploratory study was informed by interpretivism. The goal of interpretivism is to understand and find meaning in experiences from multiple subjective perspectives (Welford et al., 2011). As such theory may emerge inductively.

**Sample/Participants**

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

***Inclusion criteria***

* Adult (>18 years) survivors of critical illness
* Current or previous experience of fatigue after ICU discharge

***Exclusion criteria***

* Not yet discharged from hospital
* Lack of capacity
* Unable to speak or understand English.

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

**Data collection**

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

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

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

**Ethical considerations**

The study received university ethical approval (ETH1819-0106). Discussing critical illness experiences can be traumatic. Two experienced qualitative researchers, both of whom are registered critical care nurses (SB/LS) conducted all interviews, so appropriate support and signposting to support services such as the ICUsteps Charity (<https://icusteps.org/>) could be offered if necessary.

**Data analysis**

Anonymised and verbatim-transcribed interview data were uploaded into NVivo12 and underwent a standard process of inductive thematic analysis, using coding to identify recurring patterns and collating these into key themes (Braun and Clarke, 2005). The primary purpose was to attain descriptive data about people’s experiences of fatigue, its impact on their lives and strategies they use to mitigate its impact. The research assistant first coded all transcripts, which were reviewed by the qualitative researchers (WC-D/LS/SB) and used to produce draft themes. A consensus approach amongst the project team resolved any differences in interpretation prior to agreeing final themes.

**Rigour: Research team and reflexivity**

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

**FINDINGS**

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

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

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

Table 1: Sample characteristics

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

Table 2: Themes, subthemes and codes

**Fatigue is different for everyone**

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

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

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

Fatigue could also be unpredictable, which left people feeling out of control. One participant explained how she would be out shopping and be completely alright only to be met with an urgency to sit down: “*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, I have to sit down, I have to sit down right now*” (P13, female, age 65). Others described experiencing fatigue in a cyclical pattern: “*…it comes in cycles...I’ve had that happen a couple of times, that I’ve felt brighter and better, and then I’ve just felt really weary again*” (P10, female, age 68).

**Complex interrelating interactions**

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

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

Fatigue also affected the wider family as people struggled to engage in their normal roles as parents, partners, or children. Family members often took on additional care and support roles. One participant said: “*We had to kind of rearrange our whole lives really, my husband changed hours to make sure that he was home to do things because I couldn’t stand there and iron my son’s school uniform, I didn’t have the energy to stand up and do it*” (P2, female, age 37). Another participant described the impact on his partner, saying: “*My husband, yeah obviously he had to do so much…he sort of had to take over everything at home when I was just sitting and would fall asleep on the sofa and could not do anything. So yeah, it was difficult for him*” (P16, male, age 54).

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

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

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

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

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

**Personalised fatigue strategies**

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

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

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

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

For some people, nothing at all helped their fatigue. As one participant explained, “*I just feel like it's in the lap of the gods*” (P1, female, age 28). People had tried several things unsuccessfully. One participant said: “*I thought that if I watched TV, I might be able to keep my eyes open and be engaged with the world…I would hear the first few words of a sentence and I couldn’t be bothered because I would just fall asleep, and I never got to the end of the news section [laugh]*” (P12, female, age 63). Despite its potential benefits, exercise also proved difficult for some as highlighted by one participant: “*I would do five lengths [swimming] and I would struggle getting out of the pool*” (P2, female, age 37). In addition, some aspects of life were not necessarily modifiable. For example, one participant discussed how her age, sex and bodily changes seemed to worsen her fatigue: “*Sometimes I think it’s things like hormones and, you know, I’m going through the menopause and it could be that*” (P11, female, age 50).

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

**DISCUSSION**

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

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

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

Implications for future practice

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

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

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

Educating health and social care professionals and providing information to patients and their families improves people’s experiences, positively impacting their overall quality of life (Bench et al., 2015; Bench et al., 2016). Currently available information, for example, the ICUsteps website ([Guide to intensive care - ICUsteps](https://icusteps.org/information/guide-to-intensive-care)), the critical care recovery website ([Critical Care Recovery](https://www.criticalcarerecovery.com/)) and resources offered by the intensive care society ([Resources | Patients and relatives (ics.ac.uk)](https://ics.ac.uk/ICS/patient_and_relative/Patients___Relatives/ICS/patients-and-relatives.aspx?hkey=0a5f16cd-844e-44be-a455-c79dc6118cb2) could be further developed to better explain fatigue and its management. Our findings suggest that information resources should describe what fatigue might feel like, highlight its uniqueness to the individual, include potential reasons for fatigue, offer advice on what the patient and their family can do themselves and signpost people to appropriate support.

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

**Limitations**

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

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

**CONCLUSION**

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

**Conflict of Interest statement**

Professor Bench is a National Institute for Health Research (NIHR) 70@70 Senior Nurse and Midwifery Research Leader. Dr Shah is currently supported by an NIHR Doctoral Research Fellowship (NIHR-DRF-2017-10-094). The views expressed in this article are those of the authors and not necessarily those of the NIHR, or the Department of Health and Social Care in England.

**References**

Ågård, A.S., Egerod, I., Tønnesen, E. (2012). Struggling for independence: A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive and Critical Care Nursing,* 28, 105-113. <https://doi.org/10.1016/j.iccn.2012.01.008>

Artom, M., Czuber-Dochan, W., Sturt, J., Norton, C. (2016). Targets for health interventions for inflammatory bowel disease-fatigue. *Journal of Crohn's and Colitis,* 10, 860–869. <https://doi.org/10.1093/ecco-jcc/jjw029>

Baguley, B.J., Bolam, K.A., Wright, O.R.L., Skinner, T.L. (2017). The effect of nutrition therapy and exercise on cancer-related fatigue and quality of life in men with prostate cancer: a systematic review. *Nutrients,* 12, pii: E1003. <https://doi.org/10.3390/nu9091003>

Bench, S., Cornish, J., Xyrichis, A. (2016). Intensive Care discharge summaries for General Practice staff: a focus group study. *British Journal of General Practice*. <https://doi.org/10.3399/bjgp16X688045>

Bench, S., Stayt, L., Shah, A., Dhinan, P., Czuber-Dochan, W. (2021). Prevalence and experience of fatigue in survivors of critical illness: A mixed-methods systematic review. *Anaesthesia* <https://doi.org/10.1111/anae.15441>

Bench, S., White, C., Hopkins, P., Day, T., Griffiths, P. (2015). Evaluating the feasibility and effectiveness of a critical care discharge information pack for patients and their families: a pilot cluster randomised controlled trial. *British Medical Journal Open*, 5, e006852. <http://doi.org/10.1136/bmjopen-2014-006852>

Boyle, M., Murgo, M., Adamson H., Gill, J., Elliott, D. (2004). The effect of chronic pain on health-related quality of life amongst intensive care survivors. *Australian Critical Care,* 17, 104–113. [https://doi.org/10.1016/S1036-7314(04)80012-2](https://doi.org/10.1016/S1036-7314%2804%2980012-2)

Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <http://dx.doi.org/10.1191/1478088706qp063oa>

Cajanding, R. (2017). Causes, assessment and management of fatigue in critically ill patients. *British Journal of Nursing*, 26, 1176-1181. <https://doi.org/10.12968/bjon.2017.26.21.1176>

Carfì, A., Bernabei, R., Landi, F., for the Gemelli Against COVID-19 Post-Acute Care Study Group. (2020) Persistent Symptoms in Patients After Acute COVID-19. *Journal of the American Medical Association*, 324, 603–605. doi:10.1001/jama.2020.12603. <http://jamanetwork.com/article.aspx?doi=10.1001/jama.2020.12603>

Çelik, S., Genç, G., Yasemin, K., Aşılıoğlı, M., Sarı, M., Madenoğlu Kıvanç, M. (2016) Sleep problems, anxıety, depressıon and fatıgue on famıly members of adult intensıve care unıt patıents. *International Journal of Nursing Practice* 22, 512-522. <https://doi.org/10.1111/ijn.12451>

Choi J., Hoffman L., Schulz R., Tate, J., Donahoe, M.P., Ren, D., Given, B.A., Sherwood, P.P. (2014a). Self-reported physical symptoms in Intensive Care Unit (ICU) survivors: pilot exploration over four months post-ICU discharge. *Journal of Pain and Symptom Management,* 47, 257–270. [https://dx.doi.org/10.1016%2Fj.jpainsymman.2013.03.019](https://dx.doi.org/10.1016/j.jpainsymman.2013.03.019)

Choi, J., Tate, J., Hoffman, L. Schulz R., Ren, D., Donahoe, M.P., Given, B.A., Sherwood, P.P. (2014b). Fatigue in Family Caregivers of Adult Intensive Care Unit Survivors. Journal of Pain and Symptom Management, 48, 353–363. <http://doi.org/10.1016/j.jpainsymman.2013.09.018>

Colman, Z.E., Johnston, C.L., Ashby, S., Mackney, J.H. (2015). Experiences of fatigue following critical illness: a mixed methods study. *Physiotherapy*,101, e258-e259. <https://doi.org/10.1016/j.physio.2015.03.442>

Czuber-Dochan, W., Ream, E., Norton, C. (2013). Review article: description and management of fatigue in inflammatory bowel disease. *Alimentary Pharmacology and Therapeutics*,37, 505-516. DOI: 10.1111/apt.12205. <https://doi.org/10.1111/apt.12205>

Daniels, L.M., Johnson, A.B., Cornelius, P.J., Bowron, C., Lehnertz, A., Moore, M., Chen, Y., Schukte, P.J., Pendegraft, R.S., Hall, K.R., Bauer, P.R. (2018). Improving Quality of Life in Patients at Risk for Post–Intensive Care Syndrome. *Mayo Clinic Proceedings:* Innovations, *Quality & Outcomes*, 2, 359-369. <https://doi.org/10.1016/j.mayocpiqo.2018.10.001>

Day, A., Haj-Bakri, S., Lubchansky, S., et al. (2013). Sleep, anxiety and fatigue in family members of patients admitted to the intensive care unit: a questionnaire study. *Critical Care* 17, <http://ccforum.com/content/17/3/R91>.

Day A., Haj-Bakri S., Lubchansky S., Mehta, S. (2013) Sleep, anxiety and fatigue in family members of patients admitted to the intensive care unit: a questionnaire study. Critical Care 17, <https://doi.org/10.1186/cc12736>

Eakin, B.M.N., Patel, Y., Mendez-Tellez, P., Dingals, V.D., Needham, D.M., Turnball, A. (2017). Patients’ outcomes after acute respiratory failure: a qualitative study with the PROMIS framework. *American Journal of Critical Care,* 26, 456-465. <https://doi.org/10.4037/ajcc2017834>

Elliott, R., Yarad, E., Webb, S., Cheung, K., Bass, F., Hammond, N., Elliott, D. (2019). Cognitive impairment in intensive care unit patients: A pilot mixed-methods feasibility study exploring incidence and experiences for recovering patients. *Australian Critical Care*, 32, 131-138. <https://doi.org/10.1016/j.aucc.2018.01.003>

Friedrich, O., Reid, M.B., Van den Berghe, G., Vanhorebeek, I., Hermans, G., Rich, M.M., Larsson, L. (2015) The sick and the weak: neuropathies/myopathies in the critically ill. *Physiological Reviews*, 95, 1025-109. <https://doi.org/10.1152/physrev.00028.2014>

Geense, W., Vermeulen, H., van der Hoeven, J., van den Boogaard, M, Zegerset, M. (2017). Effective non-pharmacological interventions to prevent or mitigate long-term consequences among ICU survivors: a systematic review. *PROSPERO* 2017 CRD42017064468. Available from <http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017064468>.

Griffiths, J., Hatch, R., Bishop, J., Morgan, K., Jenkinson, C., Cuthbertson, B.H., Brett, S.J. (2013). An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12 month follow up study. *Critical Care*, 17, R100. <https://doi.org/10.1186/cc12745>

Hashem, M.H., Nallagangula, A., Nalamalapu, S., Nunna, K., Nausran, U., Robinson, K.A., Dinglas, V.D., Needham, D.M., Eakin, M.N. (2016). Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge. *Critical Care,* 20, 345. <https://doi.org/10.1186/s13054-016-1516-x>

Herdman, T.H., Kamitsuru, S. (ed). (2014). *Nursing Diagnoses - Definitions and Classification 2015-17.* (10th ed.). Nanda International inc., Wiley Blackwell.

Hosey, M. M., Needham, D.M., Kudchadkar, S.R. (2021) Fatigue in critical care survivors: multidisciplinary and self‐management strategies. *Anaesthesia.* <https://doi.org/10.1111/anae.15474>

Intensive Care National Audit and Research Centre (ICNARC). (2020) *Key Statistics from the Case Mix Programme-Adult, General Critical Care Units.* <https://onlinereports.icnarc.org>. (Accessed 22/12/2020)

John, R., Bapat, S. (2015) Intensive care unit acquired weakness. *Anaesthesia & Intensive Care Medicine*, 16, 155-158. <https://doi.org/10.1016/j.mpaic.2015.01.011>Kamdar, B.B., Suri, R., Suchyta, M.R., Digrande, K.F., Sherwood, K.D., Colantuoni, E., Dinglas, V.D., Needham, D.M., Hopkins, R.O. (2019). Return to work after critical illness: a systematic review and meta-analysis. *Thorax*, 75, 17-27. <https://doi.org/10.1136/thoraxjnl-2019-213803>

Kang, J., Jeong, Y.J. (2018) Embracing the new vulnerable self: A grounded theory approach on critical care survivors’ post-intensive care syndrome. *Intensive and Critical Care Nursing*, 49, 44-50. <https://doi.org/10.1016/j.iccn.2018.08.004>

King, J., O’Neill, B., Ramsay, P. Linden, M.A., Medniuk, D., Outtrim, J., Blackwood, B. (2019). Identifying patients’ support needs following critical illness: a scoping review of the qualitative literature. Critical Care 23, 187. <https://doi.org/10.1186/s13054-019-2441-6>

König, C., Matt, B., Kortgen, A., Turnball, A., Hartog, C.S. (2019). What matters most to sepsis survivors: a qualitative analysis to identify specific health-related quality of life domains. *Quality of Life Research*, 28, 637-647. <https://doi.org/10.1007/s11136-018-2028-8>

Kosinski, S., Mohammad, R.A., Pitcher, M., Haezebrouck, E., Coe, A.B., Costa, D.K., Prescott, H.C., Iwashyna, T.J., McSparron, J.I. (2020) What Is Post–Intensive Care Syndrome (PICS)? *American Journal of Respiratory and Critical Care Medicine,* 201, 15-16. <https://doi.org/10.1164/rccm.2018P15>

Latronico, N., Herridge, M., Hopkins, R.O., Angus, D., Hart, N., Hermans, G., Iwashyna, T., Arabi, Y., Citerio, G., Wesley Ely, E., Hall, J., Mehta, S., Puntillo, K., Van den Hoeven, J., Wunsch, H., Cook, D., Dos Santos, D., Rubenfeld, G., Vincent, J-L., Van Den Berghe, G. (2017). The ICM research agenda on intensive care unit-acquired weakness. *Intensive Care Medicine* 43, 1270-1281. <https://doi.org/10.1007/s00134-017-4757-5>

Lee, M., Kang, J., Jeong, Y.J. (2020). Risk factors for post-intensive care syndrome: A systematic review and meta-analysis. *Australian Critical Care*, 33, 287-294. <https://doi.org/10.1016/j.aucc.2019.10.004>

Maley, J.H., Brewster, I., Mayoral, I., Siruckova, R., Adams, S., McGraw, K.A., Piech, A.A., Detsky, M., Mikkelsen, M.E. (2016). Resilience in survivors of critical illness in the context of the survivors’ experience and recovery. *Annals of the American Thoracic Society*, 13, 1351-1360. <https://doi.org/10.1513/AnnalsATS.201511-782OC>

Matthews, E. (2011). Sleep disturbances and fatigue in critically ill patients. *AACN Advanced Critical Care*, 22, 204–224. <https://doi.org/10.4037/NCI.0b013e31822052cb>

McCann, S. (2016). What non-pharmacological interventions are effective in managing fatigue in patients with chronic kidney disease? PROSPERO 2016 CRD42016050289 Available from: <http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42016050289/>.

Meneses-Echávez, J., González-Jiménez, E., Ramírez-Vélez, R. (2015). Supervised exercise reduces cancer-related fatigue: a systematic review*. Journal of Physiotherapy* 61, 3-9. <https://doi.org/10.1016/j.jphys.2014.08.019>.

Nedergaard, H.K., Haberlandt, T., Reichmann, P.D., Toft, P., Jenson, H.I. (2018). Patients’ opinions on outcomes following critical illness. *Acta Anaesthesiologica Scandinavica*, 62:531-539. <https://doi.org/10.1111/aas.13058>

Neufeld, K. J., Leoutsakos, J-M.S., Yan, H., Lin, S., Zabinski, J.S., Dinglas, V.D., Hosey, M.M., Parker, A.M., Hopkins, R.O., Needham, D.M. (2020) Fatigue symptoms during the first year following ARDS. *Chest*, 158, 999-1007. <https://doi.org/10.1016/j.chest.2020.03.059>NHS England and Improvement. (2019). *The NHS Long Term Plan.* <https://www.longtermplan.nhs.uk>. Accessed 11.03.2021.

Noble, H., Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18, 34-35. <https://doi.org/10.1136/eb-2015-102054>

Ohtake, P.J., Lee, A.C., Coffey Scott, J., Hinman, R.S., Ali, N.A., Hinkson, C.R., Needham, D.M., Shutter, L., Smith-Gabai, H., Spires, M.C., Thiele, A., Wiencek, C., Smith, J.M. (201) Physical impairments associated with post–intensive care syndrome: systematic review based on the World Health Organization's International classification of functioning, disability and health framework. *Physical Therapy*, 98, 631–645. <https://doi.org/10.1093/ptj/pzy059>

Public Health England (2020) *Coronavirus (COVID-19) in the UK.* <https://coronavirus.data.gov.uk/details/healthcare>. Accessed 20th Jan 2021.

Reay, H., Arulkumaran, N., Brett, SJ., on behalf of the James Lind Alliance Intensive Care Research. (2014). Priorities for future intensive care research in the UK: results of a James Lind Alliance Priority Setting Partnership. *Journal of the Intensive Care Society,* 15, 288-296. [https://doi.org/10.1177%2F175114371401500405](https://doi.org/10.1177/175114371401500405)

Righy, C., Rosa, R.G., da Silva, R.T.A., Kochhann, R., Migliavaca, C.B., Robinson, C.C., Teche, S. P. Teixeira, C., Bozza, F.A., Falavigna, M. (2019). Prevalence of post-traumatic stress disorder symptoms in adult critical care survivors: a systematic review and meta-analysis. Critical Care, 23, 213. <https://doi.org/10.1186/s13054-019-2489-3>

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research*, 14, 1366–1386. [https://doi.org/10.1177%2F1049732304269672](https://doi.org/10.1177/1049732304269672)

Souron, R., Morel, J., Gergelé, L., Infantino, P., Brownstein, C.G., Lapole, T., Millet, G.Y. (2021). Relationship between intensive care unit-acquired weakness, fatigability and fatigue: What role for the central nervous system? *Journal of Critical Care*, 62, 101-110. <https://doi.org/10.1016/j.jcrc.2020.11.019>

Spadaro, S., Capuzzo, M., Valpiani, G., Bertacchini, S., Ragazzi, R., Dalla Corte, F., Terranova, S., Marangoni E., Volta, C.A. (2016). Fatigue in intensive care survivors one year after discharge. *Health Quality of Life Outcomes*, 14, 148. <https://doi.org/10.1186/s12955-016-0554-z>

Spadaro, S., Capuzzo, M., Volta, C.A. (2020) Fatigue of ICU Survivors, no longer to be neglected. *Chest*, 158, 848-849. <https://doi.org/10.1016/j.chest.2020.05.521>

Strahan, E.H.E., Brown, R.J. (2005). A qualitative study of the experiences of patients following transfer from intensive care. *Intensive and Critical Care Nursing*, 21, 160-171. <https://doi.org/10.1016/j.iccn.2004.10.005>

Sturges, J., Hanrahan, K. (2004). Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research,* 4, 107-118. <https://doi.org/10.1177/1468794104041110>

Tao, W., Luo, X., Cui, B., Liang, D., Wang, C., Duan, Y., Li, X., Zhou, S., Zhao, M., Li, Y., He, Y., Wang, S., Kelley, K.W., Jiang, P., Liu, Q. (2015). Practice of traditional Chinese medicine for psycho-behavioral intervention improves quality of life in cancer patients: a systematic review and meta-analysis. *Oncotarget,* 6, 39725–39739. <https://doi.org/10.18632/oncotarget.5388>

Thomas, D.R. (2017). Feedback from research participants: are member checks useful in qualitative research? *Qualitative Research in Psychology*, 14, 23-41, <https://doi.org/10.1080/14780887.2016.1219435>

Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal of Quality Health Care*, 19, 349-357. <https://doi.org/10.1093/intqhc/mzm042>

van Beusekom, I., Bakhshi-Raiez, F., van der Schaaf, M., Busschers, W.M., de Keizer, N. F., Dongelmans, D.A. (2019). ICU survivors have a substantial higher risk of developing new chronic conditions compared to a population-based control group. Critical Care Medicine 47, 324-330. https://doi: 10.1097/CCM.0000000000003576

Welford, C., Murphy, K., Casey, D. (2011). Demystifying nursing research terminology. Part 1. *Nurse Researcher*, 18, 38-43. <https://doi.org/10.7748/nr2011.07.18.4.38.c8635>

Wendebourg, M.J., Heesen, C., Finlayson, M., Meyer, B., Pöttgen, J., Köpkeet S. (2017). Patient education for people with multiple sclerosis- associated fatigue: A systematic review. *PLoS ONE*, 12, e0173025. <https://doi.org/10.1371/journal.pone.0173025>

Wintermann, G.B., Rosendahl, J., Weidner, K., Strauss, B., Hinz, A., Petrowski, K. (2018) Self-reported fatigue following intensive care of chronically critically ill patients: A prospective cohort study. *Journal of Intensive Care*, 6, 1-12. <https://doi.org/10.1186/s40560-018-0295-7>

Zlott, D.A., Byrne, M. (2010). Mechanisms by which pharmacologic agents may contribute to fatigue. *PM&R*, 2(5), 451–455. <https://doi.org/10.1016/j.pmrj.2010.04.018>