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Title: Exploring adult critical illness survivors' experiences of fatigue; a qualitative study

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ABSTRACT

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

Design and Methods: We conducted an exploratory qualitative study with 17 survivors of critical illness in the United Kingdom. One to one audio-recorded semi structured interviews, lasting up to one hour, took place 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 management. 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:

- 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: fatigue; nursing; critical illness; rehabilitation; qualitative research

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 supports the aims of the United Kingdom (UK) National Health Service (NHS) long term plan (NHSEI, 2019) Prior to the COVID-19 pandemic, nearly two thirds of patients admitted to an intensive care unit (ICU) survived, equating to approximately 30,000 people per annum within the UK and 4.85 million people in the United States (Daniels et al., 2018; ICNARC 2018). Due to COVID-19, intensive care unit (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 prevalent symptom after critical illness (Bench et al., 2021; Souron et al., 2021). Qualitative inquiry is imperative to support the development of interventions that can successfully mitigate fatigue, enabling people to engage with rehabilitation more effectively, resulting in fewer long-term problems and the ability to return to previous work and social roles. This is important for people recovering after COVID-19 as well as those with other conditions causing critical illness.

Background

Survivors of critical illness are commonly diagnosed with post intensive care syndrome (PICS), which causes a constellation of long lasting physical, psychosocial, and cognitive impairments, negatively affecting quality of life (Daniels et al., 2018; Hashem et al., 2016). Symptoms can persist for several years after hospital discharge, 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; Spadaro et al. 2016). Amongst the numerous physical and psychosocial problems associated with PICS, fatigue is a commonly reported symptom (Bench et al., 2021; Cajanding et al., 2017; Souron et al., 2021].

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). In addition to the medical diagnosis leading to an ICU admission, fatigue has been related to pain (Boyle et al., 2004; Choi et al., 2014a), comorbidities, weakness, anaemia, poor nutrition, anxiety, depression, sleep disturbances and other common environmental and situational factors such as abnormal light, noise and temperature (Bench et al., 2021; Matthews, 2011; Souron et al., 2021). Frequently used medications such as sedatives and muscle relaxants may further aggravate fatigue due to their effects on a person's mood, conscious level and/or homeostatic mechanisms (Zlott and Byrne, 2010).

A mixed methods systematic review of the literature concluded that fatigue is evident in up to 80% of survivors, predominantly measured using SF-36 vitality scores as a surrogate marker of fatigue (Bench et al., 2021). 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 showed clinically relevant fatigue symptoms at 3- and 6-months post discharge. However, a narrative review by Souron et al. (2021) report data showing that fatigue is also present many years later for some survivors. In addition, fatigue has been reported in family members of ICU survivors and linked to worsening depression and sleep quality, particularly where people experience greater symptom distress and/or a prolonged requirement for institutional care (Celik et al., 2016; Choi et al., 2014b; Day et al., 2013).

Despite the high prevalence of critical illness related fatigue, research exploring people's experiences and its impact on their lives is in its infancy. 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 (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 only as part of a wider focus on health-related quality of life after critical illness. As there is a limited qualitative data available, further qualitative research exploring patients' experience is needed.

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). (Supplementary file 1).

Design

This exploratory 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 17 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. We excluded people still in hospital, those who lacked capacity and those unable to speak or understand English. Details of included participants can be seen in table 1.

Table 1: Sample characteristics

Participants were recruited via an advert circulated on social media (Twitter and Facebook). We also asked professional colleagues to distribute study information amongst their networks. We did not offer any incentives for participation. Those who registered interest (n=34) were sent a study information sheet via email. All participants provided written or audio-recorded informed consent prior to interview. 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)

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.

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 nurses (SB/LS) conducted all interviews, so appropriate support and signposting could be offered if necessary.

Data analysis

Anonymised and verbatim-transcribed interview data were uploaded into NVivo$_{12}$ 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 (LS/SB/WC-D) 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 (AK). Interviews were performed by experienced qualitative researchers (SB/LS), one of whom is also a practicing critical care nurse, 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 with regard to 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

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 2 details the initial codes addressing each of the research questions that emerged from the interview data and informed the development of the three overarching themes: (i) fatigue is different for everyone; (ii) complex interrelating interactions; and (iii) personalised fatigue management.

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, cognitively, physically, emotionally, and socially, aspects that had a complex interaction.

Fatigue 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 also 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 also 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).

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 where 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 management

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 that 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 its impact has been highlighted by COVID-19 (Carfi et al., 2020). Our findings support those of others (Bench et al., 2021; Souron et al., 2021), showing fatigue is prevalent in people who become critically ill for many different reasons. Fatigue has also been ranked by patients as one of the most important outcomes post critical illness (Nedergaard et al.,2018). Whilst previous research identifies fatigue as a common symptom after critical illness (Bench et al., 2021; Colman et al., 2015; Spadaro et al., 2016; Souron et al., 2021; Wintermann et al., 2018), the findings from our qualitative study show each experience to be unique to the individual. Our findings also highlight that fatigue is not the same as everyday tiredness.

Our findings build on the limited research evidence currently available (Bench et al., 2021) highlighting how fatigue creates a set of complex interrelating problems that is rarely acknowledged and its impact not only the individual but on the wider family unit (Celik et al., 2016; Choi et al., 2014b; 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).

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). These include support from others, exercise (particularly swimming or being outside), alternative therapies (such as meditation), good nutrition, information and 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). Our findings emphasise the need for a personalised approach as what makes one person feel better might make another feel worse or be of no benefit whatsoever.

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. Our findings support recommendations from a narrative review by Souron et al. (2021) that tailored interventions targeting the causes of fatigue are required. 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). The attitude of friends, family, and healthcare staff is an important determinant of how people with fatigue feel about themselves. Our findings highlight how a general lack of understanding and empathy can leave people feeling ‘abnormal’ and can trigger symptoms of post-traumatic stress disorder, such as anxiety and depression, a common problem in critical illness survivors (Righy et al., 2019).

Currently available information, for example, the ICUsteps website (Guide to intensive care - ICUsteps), the critical care recovery website (Critical Care Recovery) and resources offered by the intensive care society (Resources | Patients and relatives (ics.ac.uk) 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).

Our findings highlight the need to develop assessment tools that help patients communicate their experiences of fatigue and its impact on their life. Our qualitative data should also inform the development and evaluation of future interventions, based on patient’s experiences of fatigue and their expressed support needs.

Limitations

We did not meet our target sample of 20 people. However, after the first 15 interviews limited new information emerged, and we considered data saturation likely to have occurred after 17 interviews. Due to the start of the COVID-19 pandemic, we did not pursue further data collection. Furthermore, 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. We did not 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. However, 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. Our study sample reflects a pre-COVID-19 ICU population and the robust data analysis process undertaken by the research team strengthens the findings.

CONCLUSION

This 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

XX is a National Institute for Health Research (NIHR) 70@70 Senior Nurse and Midwifery Research Leader. XX is currently supported by an NIHR Doctoral Research Fellowship (XXX). 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.

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Table 1: Sample characteristics†

Age (years)	Gender	Reason for ICU admission	LOS in ICU (Days)	Time since ICU discharge (months)	Time since hospital discharge (months)	Co-morbidities	Employment status	Living Status	Marital Status
Mean 50.76	11 Females (64%)	Sepsis n=9	Mean 25.3	Mean 34.2	Mean 29.94	None n=6	Full time n=8	Alone n=3	Married n=10
SD 12.81	6 males (36%)	ARDS/ Pneumonia n=3	SD 20.94	SD 30.38	SD 30.32	Auto-immune disorder n=2	Part-Time n=3	With Spouse/ Partner n=5	Partner n=2
		Trauma/ Neurology n=3				Asthma n=2	Retired n=4	With Partner/ Dependents n=7	Single n=5
		Cardiac condition n=3				Diverticular Disease n=1	Unemployed n=2	With Parents n=2	
						Spina Bifida n=1			
						Diabetes n=1			
						Cancer n=4			
						Aortic Aneurysm n=1			

						Anxiety/ Depression n=2			
						Renal failure n=1			

† Information provided at time of interview.

ARDS, Acute respiratory distress syndrome; ICU, Intensive care unit; LOS, length of stay; SD, standard deviation

Table 2: Themes, subthemes and codes

Theme 1: Fatigue is different for everyone (Question 1)			
Subthemes	Nature of fatigue	Types of fatigue	Pattern of fatigue
Codes	Less control over oneself, feeling entrapped, vagueness, inability to return to normal, shutting down of brain, difficulty describing fatigue, constant nature, bizarre experiences, similar to a computer virus, fuzzy mind, being poured with concrete, like treacle, unable to properly define, uncertainty, feeling trapped inside the body, alien feeling, unpredictable, all-consuming	Mental fatigue, cognitive fatigue, physical fatigue	Cyclical nature, ever-present, fluctuating, severity, factors affecting fatigue presence
Theme 2: Complex interrelating interactions (Question 2)			
Subthemes	Cognitive /mental impact	Physical Impact	Social/emotional Impact
Codes	Cognitive load, confusion regarding condition, confusion regarding recovery, denial about condition, excessive worrying, hazy memory, inability to comprehend fatigue, inability to focus, inability to recall, increased forgetfulness, mental impact of critical care	Lack of energy, feeling of heaviness/pressure on body, increased tiredness, physical strain, feeling sore, weight changes, poor attention to physical appearance, inability to move, inability to function properly, increased sluggishness	Reduced social activities, difficulty communicating, social exhaustion, impact on relationships, impact on family life, impact on family, social expectations, feelings of embarrassment, undesirable impact on career, impact on daily life, adjustments to social life, struggle to go out
Theme 3: Personalised fatigue management (Questions 3 and 4)			
Sub-themes	Things that help	Factors that worsen fatigue	Strategies
Codes	Social networks, power of exercise, having a pet, being in rehab, use of internet, reassurance from mental health expert, support from medical staff, support from family, having a drink, distracting oneself, community response team,	Socialising, effects of medication, exhaustion due to work, effect of old age, ignorance from medical staff, lack of acceptance socially, lack of empathy, lack of help, trivialisation of	Alternative therapy, medicines, good nutrition, education of fatigue can be improved, amount of sleep, need to target factors in a positive way

	gardening, reading, watching television, importance of not victimising oneself, self-help strategies, self-reassurance	fatigue, not being taken seriously	