**Corresponding author**

Professor Suzanne Bench

School of Health and Social Care, London South Bank University

103 Borough road, London SE1 0AA, UK

**Prevalence and experience of fatigue in survivors of critical illness: A mixed-methods systematic review***

S. Bench,[1] L. Stayt,[2] A. Shah,[3] P. Dhiman,[4] and W. Czuber-Dochan[5]

1 Professor, School of Health and Social Care, London South Bank University, London, UK

2 Senior Lecturer, Oxford Brookes University, Oxford, UK

3 NIHR Doctoral Research Fellow, Radcliffe Department of Medicine, University of Oxford, Oxford, UK

4 Senior Statistician, Centre for Statistics in Medicine, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, UK

5 Senior Lecturer and Associate Dean, Florence Nightingale School of Nursing, Midwifery and Palliative care, King's College London, UK

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**Correspondence to:** S. Bench

**Email**: benchs@lsbu.ac.uk

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**Twitter handles**: @szbench; @LouiseStayt; @DocAShah; @OUHCritCare

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**Summary**

We conducted a mixed methods systematic review to investigate the prevalence, experience and management of fatigue in survivors of critical illness. We identified 76 studies investigating fatigue or vitality in adults discharged from an ICU, and split the data we extracted into three datasets: vitality scores from the Short Form Health Survey-36 (n=54); other quantitative data (n=19); and qualitative data n =9). We assessed methodological quality using critical appraisal skills programme tools. We adopted a segregated approach to mixed-methods synthesis. In a final step, we attributed combined results to one of four qualitative themes: prevalence and severity; contributing factors; impacts on quality of life; and assessment and management. Prevalence of fatigue ranged from 13.8 to 80.9%. Short Form Health Survey-36 vitality scores were commonly used as a marker of fatigue. Vitality scores reached a nadir approximately one month post-ICU discharge (mean (SD) 56.44 (32.30); 95%CI 52.92 - 59.97). They improved over time, but seldom reached reference population scores. Associated biological, disease-related and psychological factors included age, poor pre-morbid status, sleep and psychological disturbance. Qualitative data highlight the profound negative impact of fatigue on survivors' quality of life. Survivors seldom had any information provided on the potential impact of fatigue. No fatigue assessment tools specific to critical illness or evidence-based interventions were reported. Fatigue is highly prevalent in survivors of critical illness, and negatively impacts recovery. Further research on developing fatigue assessment tools specifically for critically ill patients and evaluating the impact of pharmacological and non-pharmacology interventions is needed.

**Introduction**

Every year, more than 130,000 patients survive an episode of critical illness in the UK [1]. Survivors commonly report long-lasting physical, cognitive and psycho-social problems impacting their quality of life, a combination termed post-intensive care syndrome [2, 3]. Post-intensive care syndrome can also impact on the family members of survivors [4]. A cardinal symptom of post-intensive care syndrome is fatigue [5], which is defined as an overwhelming, sustained sense of exhaustion, typically unrelieved by sleep, with decreased capacity for physical and mental work at a usual level [6, 7].

Recent data suggest that fatigue is an important, but under-recognised and under-researched problem in survivors of critical illness [8, 9, 10]. In a qualitative study by Nedergaard et al., former patients ranked fatigue as one of three outcomes most important to them [11]. International advisory panels also highlight the need for research investigating the prevalence, severity, and underlying mechanisms of fatigue and the design of strategies to optimise support during patients' recovery [12, 13]. Moreover, although the long-term consequences of COVID-19 are unknown, preliminary reports suggest that fatigue is the most prominent symptom for many survivors [14].

Previous reviews have evaluated overall health-related quality of life (HRQoL) following critical illness, and reported some data on fatigue, for example by Hashem et al. [5] Two narrative reviews that included data on the assessment and management of fatigue in the intensive care unit (ICU) have also been published [15, 16]. In this mixed-methods systematic review we aimed to identify the prevalence, experience, risk factors for and management of fatigue in adult critical illness survivors following ICU discharge.

**Methods**

We conducted this systematic review according to a study protocol pre-registered on PROSPERO. We report our findings in accordance with the preferred reporting items for systematic reviews and meta-analysis (PRISMA) statement [17]. We undertook a mixed-methods approach, combining studies from different research methodologies in accordance with best practice guidance [18].

We considered primary research of any methodology published in English. We included studies investigating fatigue in adult patients who had been in an ICU. We excluded studies that focused on fatigue secondary to a solitary pathological process (e.g. brain injury) and those on a different, but parallel topic (e.g. sleepiness). We also excluded studies reporting data collected whilst the patient was still in the ICU. Due to the extensive number of studies reporting Medical Outcomes Study 36-item Short Form Health Survey (SF-36) data as part of overall HRQoL, we included only papers published after 2000 and which reported raw vitality data as a measure of fatigue.

We searched seven databases from 01 Jan 1946 until 28 Feb 2018: CINAHL®; MEDLINE®; EMBASE®; PsycINFO®; OVID® Emcare; British Nursing Index; and the Web of Science™. An updated search was conducted on 14 May 2020. The search strategy can be found in online Supporting Information Table S1. We also contacted known experts and searched professional websites using the terms fatigue and vitality. We performed forward and backward citation searches on all studies that met the inclusion criteria.

A single reviewer screened all titles and abstracts, and two authors independently reviewed the full text of selected studies against the eligibility criteria. We resolved any discrepancies through discussion and consensus. Figure 1 presents results of the search and sifting process.

We collated the extracted data onto pre-piloted forms. We assessed methodological quality using the critical appraisal skills programme (CASP) tools [19]. No study was excluded on the basis of its methodological quality, but we assigned each included study a grade (green, amber, red) based on the quality and strength of the evidence reported (Table 1). Consensus agreements by the whole team determined final decisions.

We adopted a segregated approach to mixed-methods synthesis [18]. We split extracted data into three datasets for analysis: data from the vitality domain of the SF-36 (Dataset A); other quantitative data (Dataset B); and qualitative data (Dataset C). In a final step, we merged all datasets, attributing all results to one of the identified qualitative themes.

Mean SF-36 vitality domain scores, standard deviation and sample size were extracted for each reported time point. Mean vitality scores were combined to produce a weighted mean score. Indication of ICU admission type was categorised as: unselected general cohort; sepsis; or surgery. The weighted mean vitality score, standard deviation and 95% confidence intervals were collated for each study design. Studies presenting median SF-36 vitality score were not included in this analysis. Although both mean and median vitality scores were presented in included studies, access to the raw data was not always available to confirm their normality assumption. We assumed that where means were presented, data were normally distributed, and where median was presented, data were not normally distributed. Due to both mean and median values being presented, we were unable to combine all scores, and so only present the summary of the mean vitality scores at each time point. We used STATA (Version 15; StataCorp, College Station, Texas, USA) for analysis of Dataset A.

Pooling of results from other quantitative data (Dataset B) was not possible due to the heterogeneity of assessment tools used to measure fatigue; results are thus presented

narratively. Qualitative data (Dataset C) were subjected to a standard process of thematic analysis [20]. A single researcher manually coded extracted data and identified initial themes. These were reviewed by a second researcher and a consensus approach involving the whole team used to determine final decisions.

**Results**

We included 76 studies (Fig. 1). Full details of included quantitative and qualitative studies can be found in online Supporting Information Tables S2 and S3, respectively. Sixty-one of the 76 included studies were observational, six were randomised controlled trials (RCTs), six were qualitative and three were mixed methods studies [8-11, 21-92]. Forty-four studies were conducted in Europe, 13 in Australasia, seven in North America, and eight in other parts of the world (Argentina, China, Iran, Morocco, South Africa, South Korea). Most studies (n=53 (73%)) were single centre; and were investigating a general/unselected ICU patient cohort (n=45 (62%)).

The majority of quantitative studies (n=54) used SF-36 vitality scores as a marker of fatigue; however, 19 studies used a specific fatigue assessment tool. Only one of the qualitative studies focused specifically on fatigue [34], whilst all others evaluated fatigue as part of a wider focus on HRQoL after critical illness. Two of the qualitative studies also reported data from the perspective of relatives [22, 23].

Follow-up assessments were most commonly evaluated 6-12 months after ICU or hospital discharge (online Supporting Information Table S4). Nine studies evaluated outcomes at two or more years following hospital discharge. Only two studies collected pre-ICU/hospital admission vitality data and eight studies collected vitality data at the point of ICU discharge.

Studies were generally of adequate quality, defined by a subjective rating of amber or green (Table 1). Follow-up rates for SF-36 studies exceeded 70% in 25 (52%) studies, with a median (IQR [range]) response rate of 71.5% (48.7-82.3 [14.2-100]). Response rates in Dataset B ranged from 35% to 100%. Response rates were higher in studies that used face-to-face assessment, or a combination of methodologies (online Supporting Information Table S4). However, vitality or fatigue was commonly a secondary outcome measure, and few of the observational studies adequately identified and considered all confounding factors. Several qualitative studies also provided insufficient data to allow a full judgement of quality. Regardless of methodological quality ratings, all data were treated equally during analysis.

Synthesised results are reported under the four identified qualitative themes: prevalence and severity; contributing factors; impacts on quality of life; and assessment and management.

The reported prevalence of fatigue ranged from 13.8% at one year to 80.9% four months post-ICU discharge [8, 32, 51, 68, 70]. Vitality scores reached a nadir at one month following ICU discharge and slowly improved over time (Table 2 and Fig. 2) but remained worse than the reference population in most studies until follow-up was complete. Vitality scores obtained from RCT data were lower than those from cohort studies (Fig. 2).

Qualitative findings support fatigue as a commonly experienced symptom post ICU discharge, with people describing it as a complex symptom rather than simple muscle weakness [59]. Fatigue was particularly prevalent in the early period after ICU discharge [22, 34, 83] and, for many people, fatigue symptoms and vitality improved over time [43, 63]. Fatigue was generally viewed as an expected and integral part of recovery; "*I just think of it as getting over what I've been through*" [34]. However, recovery took time and survivors

were surprised by this; *"…I am similarly stunned at the time it's taken to get to the point where I am at*" [47].

A range of factors were reported to be contributing, and were associated with fatigue following ICU discharge; these are summarised in Table 3. However, they were not consistently observed across all studies.

Fatigue was reported to have a profound impact on quality of life, including cognitive, physical and social dimensions of an individual's functioning [34]. Fatigue was also associated with a significantly lower Barthel Index at discharge [10] and was a commonly cited cause of reduced physical function [61], as described by one person who said; "*I can't walk very far. I've just got no energy*" [47]. This affected peoples' independence with regards to their personal care, as described by a participant in a study by Strahan et al.; *''… somebody has to take me for a shower and that exhausts me*" [83]. Fatigue also impacted on wider activities, highlighted in the following quote; "*I can only do one thing a day. If I had two appointments, I couldn't make it because I would be exhausted even before I finished the first one*". [59] Long-term iron deficiency was also reported to impact fatigue preventing a return to pre-ICU admission daily activities [82].

Fatigue was linked to a greater risk of being diagnosed with depression [11]. Survivors also reported losing their identity and their self-worth, because they were unable to look after themselves or to perform their normal social roles, such as being a parent or partner [22, 34]. Fatigue affected both employed and retired participants' ability to return to their previous level of activity [51] and had a financial impact; "*I'd lost the business, … we were in debt to the bank... We had no money coming in, we couldn't pay the mortgage… Just all*

*those money worries*" [34]. Being unable to work also impacted on people's status within the family, making them feel a burden [59].

Survivors often had little energy for social activities such as interaction with friends and family [22]. The social impact was made worse by what was described as 'cognitive fatigue', leaving people with difficulties with concentration, memory and thought processing; "*I would think, oh, I wish this was over. I want to go home and have a sleep…. things like laughing and being humorous…that's not really important when you're trying to do the basics of having a conversation*" [34].

In addition to the SF-36, 11 tools were used, either in their original form or as a modified version, to measure the presence, severity or impact of fatigue (Table 4).

Tools varied in length from 40 items (Fatigue Impact Scale (FIS)) to 20- or 18-items (Multidimensional Fatigue Inventory-20 (MFI-20) and Lee Fatigue Scale (LFS) respectively), down to 13, 9 or 8 items (Functional Assessment of Chronic Illness Therapy for Fatigue (FACIT-F), Fatigue Severity Scale-9 (FSS-9), Checklist individual strength-fatigue (CIF-F)), with some being just a single item (e.g. Visual Analogue Scale (VAS)).

Some tools were designed solely to measure fatigue, while others had a sub-section or one question designated to assess fatigue, or related constructs. Different scales provided different information on fatigue. This ranged from a simple 'Yes/No' answer such as on the Symptom Assessment Tool, or a rating of severity using, for example, a VAS numerical scale. Some tools used more discreet severity scores for different fatigue domains such as general fatigue, physical fatigue, mental fatigue, reduced motivation, and reduced activity or cognitive, physical and psychosocial impact of fatigue.

Causes of fatigue were assessed in only two studies using the FSS-9 [47, 75] and only three studies used one of two tools (FIS and FSS-9) to measure the impact of fatigue [34, 47, 75]. None of the tools were developed with critical illness survivors and only two, the FACIT-F scale and MFI-20, were validated in former ICU patients. Spadaro et al. stated that the reliability and construct validity data they collected suggested that the FACIT-F scale grasped the negative aspects of fatigue better than the vitality dimension of SF-36, whilst Wintermann et al. reported the MFI-20 to have a Cronbach's α of 0.91 [9, 10].

People reported using a range of strategies to mitigate and manage their fatigue. As well as trying to eat well and taking regular naps to avoid feeling 'wiped out' [22, 34, 43], exercise was seen as beneficial; "*any tiredness I had after that [exercise] I felt was a natural tiredness, not just a tiredness from being unwell*" [34]. This included trying to exercise the brain by doing things like puzzles, although the ability to do this was limited by the fatigue itself; "*When I play it [Sudoku] and the time it takes for me to do it is all related to the fatigue factor and the concentration factor so if I am fatigued it takes forever to do it and I just have to put it down*" [47].

Survivors also reported pacing activities and prioritising as useful strategies [34, 47, 59]. Planning ahead and being organised helped people to continue with their daily activities; "*I do have to write on the calendar… I had the whole week planned… and I had to write it all down to make sure I knew exactly what I was doing*" [43].

Finally, education and information about fatigue, its impacts and how to manage it was considered important, but difficult to obtain; "*Nobody forewarned us about anything…. Even if a doctor sat you down and said to you 'you can expect to be very tired for the next two*

*years. You're going to get fatigue… Expect this*", whilst another said "*The fatigue part of it has never been broached. Never*" [34].

**Discussion**

In this most comprehensive review to date, we have demonstrated the following: 1. fatigue is common in critical illness survivors with a prevalence ranging from 13.8 to 80.9%; 2. fatigue severity reaches its nadir at approximately one month post-ICU discharge, improves over time but seldom reaches reference population scores; 3. there is no critical illness-specific tool to assess fatigue in ICU survivors; and 4. there is a paucity of evidence-based interventions for managing fatigue, despite it having a profound negative impact on survivors' quality of life. Our findings support systematic reviews published on other long-term conditions, including: cancer [94]; inflammatory bowel disease [95]; and chronic kidney disease [96], highlighting fatigue as a commonly experienced symptom of ill health.

Fatigue is multifaceted and multifactorial, and related to a variety of modifiable and non-modifiable factors. The variety of scales used to assess fatigue make it difficult to compare severity, types and impact between studies and across patient populations. We recommend the development of a critical illness-specific fatigue assessment tool. Tools used to assess fatigue to date have been developed for other population groups, e.g cancer; chronic fatigue; inflammatory bowel disease; and stroke [97-100]. Two fatigue assessment tools have been validated in a critical care population [9, 10], however, none have been developed with or for ICU survivors.

The prevalence of fatigue reported in studies included in our review was extremely wide (13.8 to 80.9%). This is likely due to the heterogeneity of methodologies employed, the range of tools used for assessment and the different time points at which researchers

measured outcomes. Fatigue severity reaches a nadir at one-month post-ICU discharge and demonstrates the greatest improvement in the first year after discharge. Interventions to treat fatigue may, therefore, be most effective in this time period.

To address its multidimensional nature, fatigue management requires a complex intervention. Findings of our review and those with other population groups suggest a tailored, multifaceted approach with recommendations for nutrition, exercise, pacing activities and education/information [101-105]. Outside of critical care, non-pharmacological interventions have proved effective in community-dwelling older adults [106]. Alternative therapies [107] and pharmacological interventions such as iron, modafinil and doxepin, have also been evaluated, with the latter two proving effective in patients with Parkinson's disease [108].

The estimates in this review can be used to inform power calculations for future long-term trials, which should include collection of pre-ICU fatigue/vitality data for comparison where possible. Conducting long-term outcome research in critical illness survivors is challenging, however more than half of included studies in our review had follow-up rates of greater than 70%.

Further qualitative study is needed to better understand critical illness fatigue, from the perspective of both patients and their family members. The impact of critical illness on family members' fatigue remains an unexplored area and is a strong recommendation for future research. Despite Choi et al. reporting that fatigue is also experienced by family members [33], our original search failed to uncover enough data to review further.

Employing a mixed-methods approach enabled us to produce a comprehensive review of all

available evidence, with estimates that can inform power calculations for future studies (Table 2). Our review also identifies factors, which may increase or mitigate against fatigue (Table 3), that researchers might find useful in the future when designing interventional studies. Our review has limitations. Meta-analysis of the vitality data was not possible due to the degree of heterogeneity. Additionally, alongside fatigue often being studied as a secondary outcome measure, differences in study design, patient populations, fatigue measurement tools, follow-up time points and response rates of the studies included in our review make it difficult to provide one overall conclusion.

In summary, this mixed method review shows that fatigue is highly prevalent in critical illness survivors, negatively impacting their recovery after discharge. To date, no critical illness-specific fatigue assessment tool or targeted intervention has been specifically designed to manage this symptom. Our review identifies factors that may increase or mitigate against fatigue, along with potential management strategies, which should be used to inform future research and practice.

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**Table 1** Included studies and their methodological quality rating

| Study | Dataset | Type of study | Quality rating | Study | Dataset | Type of study | Quality rating |
|---|---|---|---|---|---|---|---|
| Abelha et al. [21] | A | Cohort | Green | Kaarlola et al. [58] | A | Cohort | Green |
| Ågård et al. [22] | C | Qualitative | Green | Kang & Jeong [59] | C | Qualitative | Green |
| Agren et al. [23] | A | RCT† | Red | Kayambu et al. [60] | A | RCT† | Green |
| Aitken et al. [24] | A | Cohort | Green | Kelly & McKinley [61] | A | Cohort | Red |
| Bäckman et al. [25] | A | Cohort | Amber | Khoudri et al. [62] | A | Cohort | Green |
| Bakhru et al. [26] | A | Cohort | Red | König et al. [63] | C | Qualitative | Green |
| Bapat et al. [27] | A | Cohort | Green | Kowalik et al. [64] | A | Cohort | Green |
| Baranyi et al. [28] | A | Cohort | Amber | Kress et al. [65] | A | RCT† | Green |
| Battle et al. [29] | A | Cohort | Green | Kvale & Flaatten [66] | A | Cohort | Amber |
| Bocci et al. [30] | B | Cohort | Amber | Lagercrantz et al. [67] | A | Cohort | Red |
| Boyle et al. [31] | A | Cohort | Amber | Langerud et al. [68] | B | Cohort | Green |
| Chaboyer et al. [32] | A | Cohort | Amber | Lasocki et al. [69] | B | Cohort | Red |
| Choi et al. [8] | B | Cohort | Green | Maley et al. [70] | C | Mixed‡ | Green |
| Choi et al. [33] | C | Qualitative | Green | Needham at al. [71] | B | Cohort | Green |
| Colman et al. [34] | B & C | Mixed‡ | Green | Nesseler et al. [72] | A | Cohort | Green |
| Combes et al. [35] | A | Cohort | Green | Orwelius et al. [73] | A | Cohort | Amber |
| Contou et al. [36] | A | Cohort | Amber | Pettilä et al. [74] | A | Cohort | Green |
| Cuthbertson et al. [37] | A | Cohort | Green | Raggi et al. [75] | B | Cohort | Red |
| Cuthbertson et al. [38] | A | Cohort | Green | Roll et al. [76] | A | Cohort | Amber |
| Daffurn et al. [39] | B | Cohort | Green | Rosendahl et al. [77] | B | Cohort | Green |

| | | | |
|---|---|---|---|
| Das Neves et al. [40] | B | Cohort | Green |
| Deja et al. [41] | A | Cohort | Amber |
| Denehy et al. [42] | A | RCT† | Green |
| Eakin et al. [43] | C | Qualitative | Green |
| Eddleston et al. [44] | A & B | Cohort | Amber |
| Elliott et al. [45] | A | Cohort | Amber |
| Elliott et al. [46] | A | RCT† | Green |
| Elliott et al. [47] | B & C | Mixed‡ | Red |
| Ferrand et al. [48] | A | Cohort | Green |
| Flaaten & Kvale [49] | A | Cohort | Green |
| Rothenhäusler et al. [78] | A | Cohort | Amber |
| Schandl et al. [79] | A | Cohort | Amber |
| Schneiderman [80] | A | Cohort | Amber |
| Skinner et al. [81] | A | Cohort | Amber |
| Spadaro et al. [9] | B | Cohort | Green |
| Steenbergen et al. [82] | A & B | Cohort | Green |
| Strahan et al. [83] | C | Qualitative | Green |
| Stricker et al. [84] | A | Cohort | Red |
| Su et al. [85] | A | Cohort | Amber |
| Svenningsen et al. [86] | A | Cohort | Amber |

**Table 2** SF-36 Vitality scores of included studies over time. Values are mean (SD) with 95% Confidence Intervals

| **Study design (n = no. of studies)** | **Baseline** | **1 month** | **3 months** | **6 months** | **9 months** | **12 months** | **24 months** | **60 months** |
|---|---|---|---|---|---|---|---|---|
| | | | | **(n = no. of study participants providing vitality data)** | | | | |
| Cohort (n = 38) | 49.71 (25.75) [48.44 -50.98] (n = 1586) | 46.18 (22.80) [44.48 - 47.88] (n = 690) | 53.56 (22.72) [52.36 - 54.76] (n = 1370) | 55.40 (24.05) (54.39 - 56.41) (n = 2194) | UA* | 53.78 (24.07) [52.83 - 54.73] (n = 2464) | 55.69 (22.13) [54.61 - 56.77] (n= 1610) | 57.02 (22.29) [54.79 - 59.25] (n = 387) |
| RCT† (n = 5) | 38.91 (12.99) [36.43 - 41.39] (n =108) | UA* | 42.80 (12.02) [40.44 - 45.16] (n = 102) | 43.45 (13.92) [41.17 - 45.73] (n = 145) | UA* | 45.65 (12.91) [42.70 - 48.38] (n = 82) | UA* | UA* |
| Cross-sectional (n = 8) | UA* | 56.44 (32.3) [52.92 - 59.97] (n = 325) | 50 (18.5) [46.96 - 53.04] (n = 145) | UA* | UA* | 54.66 (16.1) [52.83 - 56.49] (n = 299) | UA* | UA* |
| Case-control (n = 2) | UA* | UA* | UA* | UA* | UA* | 71.63 (18.86) [67.29 - 75.97] (n = 75) | UA* | UA‡* |
| Before-and-after (*n*=1) | UA* | UA* | UA* | UA* | 10.08 (n = 19) | UA* | UA* | UA* |

RCT, randomised controlled trial; UA, Unavailable (insufficient data on mean or standard deviation)

**Table 3** Factors associated with fatigue in ICU survivors. Data are number of studies

| **Negative impact** | **Positive impact** |
|---|---|
| Patient / demographic<br>• Female sex (n = 3) [21,44,50]<br>• Age – both increasing age [10,48,50,57,92] and young age, especially in males (n = 5) [21]<br>• Poor pre-morbid vitality/quality of life scores (n = 3) [10,37,51,75]<br>• High pre-existing co-morbidity (n = 2) [10,7<br>Admission/ICU-related<br>• High ICU admission illness severity scores (n = 3) [48,50,62]<br>• Multiple organ dysfunction (n = 1) [74]<br>• Severe sepsis/septic shock (n = 2) [29,93]<br>• Prolonged ventilation (n = 2) [48,92]<br>• ICU length of stay (n = 2) [27,50]<br>• Hydroxyethyl starch fluid resuscitation (n = 1) [91]<br>• Traumatic brain injury (n = 1) [50]<br>• Cognitive impairment (n= 1) [78]<br>• Muscle weakness (n= 4) [8,30,53,69)<br>• Iron deficiency (n = 1) [69]<br>Psychological / constitutional<br>• Pain (n = 5) [8,30,31,39,68)<br>• Sleep disturbance (n = 6) [8,30,39,44,47,68]<br>• Depression and/or anxiety (n = 4) [10,30,68,75]<br>• PTSD or PTSS (n = 2) [10,68]<br>• Breathlessness / dyspnoea (n = 1) [9]<br>• Weight loss (n = 1) [53]<br>Social<br>• Lack of social support (n = 1) [10]<br>• Discharged home following ICU (n = 1) [8]<br>• Unable to return to employment (n = 1) [53] | • Psychoeducational (n = 1) [23]<br>• Increased 6-minute walking distance (n = 1) [24]<br>• ICU diaries (n = 1) [25]<br>• Mild therapeutic hypothermia (following out of hospital cardiac arrest) (n = 1) [64] |

ICU, Intensive Care Unit; PTDS, Post-traumatic stress disorder; PTSS, Post-traumatic stress symptoms

**Table 4** Assessment tools used to evaluate fatigue

| Tool | Item measured | Tool description | Version | Study reference |
|---|---|---|---|---|
| Fatigue Severity Scale (FSS-9) | Cause/ Presence/ Severity/ Impact | Nine items using seven-point scale. Higher score indicates greater impact of fatigue. | Original | Raggi et al. [75]; Elliott et al. [47] |
| Fatigue Impact Scale (FIS) | Functional impact | 40-item questionnaire. Likert-like scale of 0-4, with a sub-score calculated for each dimension of fatigue (cognitive, physical and social) occurring in the preceding four weeks. | Original | Colman et al. [34] |
| Functional Assessment of Chronic Illness Therapy for Fatigue (FACIT-F) scale | Presence/ Severity | 13 items referring to the previous seven days. Final score ranges from 0 - 52; higher scores represent less fatigue. | Original | Needham et al. [71]; Spadaro et al. [9] |
| Lee Fatigue Scale (LFS) | Presence/ Severity | 18-item -13 fatigue and five energy scale (no symptoms (0) to very high symptoms (10)). Total score calculated as mean. | Original | Langerud et al. [68] |
| Checklist individual strength-fatigue (CIS-fatigue) scale | Severity/ Impact | 8 questions scoring on a 7-point Likert scale. (range 8–56). | Dutch Version | van Vliet et al. [88] |
| Multidimensional Fatigue Inventory-20 (MFI-20) | Presence/ Severity/ Type | 20-item self-report measure covering five dimensions: General Fatigue, Physical Fatigue, Mental Fatigue, Reduced Motivation, Reduced Activity. Minimum score 4 (absence of fatigue) and maximum of 20 for each subscale. | French version<br>Original | Lasocki et al. [69]<br>Wintermann et al. [10] |
| Symptom Assessment Tool | Presence | Fatigue one of 10 symptoms on which people self-report (Yes/No) | Modified version | Choi et al. [8] |

| | | | | |
|---|---|---|---|---|
| Giessen Subjective Complaints List | Presence/ Severity | Four subscales, one of which is exhaustion, rated on 5-point scale from 0 (not at all) to 4 (very much) | Original | Rosendhal et al. [77] |
| WHOQOL-BREF | Presence | One of 26 questions (subset of Physical health domain); "*Do you have enough energy for everyday life?*" | Original | König et al. [63] |
| Visual/ Numerical analogue scale | Presence/ Severity | Measure of global fatigue/11-point (0 = worst fatigue possible, 10 = normal) | Part of FSS-9 | Elliott et al. [47] |
| | | 0 (not tired) to 10 (exhausted). | Own version | Lasocki et al. [69] |
| | | Range, 0 (no symptoms) to 10 (worst symptoms) | Own version | Walsh et al. [90] |
| | | Three-point scale | Own version | Eddleston et al. [44] |
| Local questionnaire | Presence | 15 item questionnaire regarding ICU complications including fatigue | Own version | Steenbergen et al. [82] |
| | Presence | 14 item questionnaire, one question on fatigue; "*Currently, do you feel more fatigue than before the ICU stay*" Yes/No | Own version | Granja et al. [51] |
| | Presence/ Severity | One question asking whether fatigue was absent, mild, moderate or severe | Own version | Bocci et al. [30] |

**Captions for Figures**

**Figure 1** PRISMA diagram

**Figure 2** Mean (95%CI) SF-36 vitality scores over time for data from (a) observational cohort studies and (b) randomised controlled trials

**Online supporting information**

**Table S1** Search strategy terms

**Table S2** Study characteristics of included quantitative studies

**Table S3** Study characteristics of included qualitative studies

**Table S4** Follow up methods, duration of follow-up and response rates

**Supplementary Table 1** Search strategy terms.

| Population | Phenomena of interest | Context |
|---|---|---|
| Patients (MeSH) | Fatigue (MeSH) | Critical illness (MeSH) |
| Patient* | Fatigue* | Critical Care (MeSH) |
| Family (MeSH) | Tiredness | Intensive care |
| Relative* | Tired* | ITU |
| Survivors (MeSH) | Vigour* | ICU |
| Survivor* | Vitality | Intensive therapy |
| Family member* | Lethargy (MeSH) | (intensive or critical*) ADJ5 (ill* or care) |
| Family caregiver* | Letharg* | |
| (relative* or famil*) ADG6 ((carer* or caregiv* or (care ADJ3 provid*)) | | |

**Supplementary Table 2** Study characteristics of included quantitative studies. Values are number (proportion), mean (SD) and median (IQR). Full range was not reported in the relevant studies.

| Reference | Country | Study design | Included participants | Age (years) | Sex (majority) | Admission illness severity score | Key findings |
|---|---|---|---|---|---|---|---|
| Surgery | | | | | | | |
| Abelha et al. [21] | Portugal | Prospective cohort, single centre | Non-cardiac surgery | 66 (55-74) | M: 240 (64%) | SAPS II: 21 (15-31) | VT scores lower in females and younger males |
| Agren et al. [23] | Sweden | RCT, single centre | Heart failure post-cardiac surgery | Control 69 (8.4); Intervention 70 (9.1) | M: 37 (88%) | EuroSCORE: Control 9.8 (4.3) Intervention 7.8 (3.2) | VT scores higher in intervention (psychoeducational support) group at 3 and 12 months |
| Bapat et al. [27] | UK | Prospective cohort, single centre | ICU >5 days, complicated cardiac surgery | Survivors 67.5; Non-survivors 69.8 | M: 109 (73%) | EuroSCORE: 6.4 (0.5) | VT scores lower in patients with prolonged / complicated ICU stay |
| Baranyi et al. [28] | Germany | Prospective cohort, single centre | Solid organ transplantation | 52.4 (11.6) | M: 87 (69%) | NR | Overall VT scores lower compared with controls, post traumatic stress symptoms associated with lower VT scores |
| Fu et al. [50] | China | Prospective cohort, single centre | Trauma ICU survivors | 47.8 (14.5) | M: 275 (79%) | ISS: 18.7 (9.4) SAPS: 23.8 (12.7) | Age, sex, ICU LOS, higher ISS and head injury associated with lower VT scores |
| Lagercrantz et al. [67] | Sweden | Retrospective cohort, single centre | Cardiac surgery, ICU >10 days | 68 (11) | NR | EuroSCORE: 7.8 (3.2) | Lower VT scores compared with population norms |
| Vogel et al. [89] | Sweden | Prospective cohort, single centre | General surgical ICU stay $\geq$ 96 hrs | 66 (58-74) | M: 182 (66%) | APACHE II (16-25) | Lower VT scores compared with population norms |
| Sepsis | | | | | | | |
| Bakhru et al. [26] | USA | Prospective cohort, single centre | ICU >24 hrs, septic shock and/or requiring MV | 64.5 (27.5) | M: 19 (53%) | APACHE II: 28.5 (8.0) | No difference in VT scores in those re-admitted at 6 months and those that died at 1 year, compared with |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | those that weren't |
| Battle et al. [29] | Wales | Prospective cohort, single centre | SIRS, Sepsis in emergency department or ICU | 58 (30) | F: 27 (54%) | SOFA: 3 (4) | Overall VT scores lower compared with controls. Septic shock associated with lower VT scores than uncomplicated sepsis or SIRS |
| Contou et al. [36] | France | Case control, multicentre | Septic shock with and without purpura fulminans (PF) | PF: 43 (25-61); Non-PF: 53 (37-63) | F: 45 (61%) | SAPS II: 42 (30-56) | Lower VT scores in subgroup of patients who required amputation |
| Heyland et al. [54] | Canada | Cross-sectional, single centre | Sepsis admission | 62 (13.7) | M: 16 (53%) | APACHE II: 22.4 (6.0) | Lower VT scores compared with population norms |
| Hofhius et al. [55] | Netherlands | Prospective cohort, single centre | ICU >48 hours, severe sepsis | 70 (62-77) | M: 108 (64%) | APACHE II: 20 (15-24) | Improved VT scores at 6 months but lower than pre-ICU admission score |
| Kayumba et al. [60] | Australia | Pilot RCT, single centre | Sepsis and MV ≥48hrs | Control group 65.5 (37-85); Study group 62.5 (30-83) | M: 32 (64%) | APACHE II: Control 27 (6.8) Intervention 28 (7.6) SOFA: Control 10.5 (2.5) Intervention 11.1 (3.2) | No significant difference in VT scores at 6 months with or without early mobilisation |
| Nesseler et al. [72] | France | Prospective cohort, single centre | Sepsis admission | 69 (61-78) | M: 65 (70%) | SOFA: 10 (9-11) SAPS II: 54 (40-60) | Lower VT scores compared with population norms but improved between baseline and 180 days |
| Pettilä et al. [74] | Finland | Prospective cohort, single centre | Sepsis admission | 53 (16.4) | M: 188 (62%) | APACHE II: 12.8 (7.3) | Lower VT scores at compared with population norms with multiple organ dysfunction associated with lower VT scores. |
| Rosendahl et al. [77] | Germany | Nationwide cohort | Sepsis survivors 2- 120 months post ICU discharge | 61.1 (11.5) | M: 37 (67%) | N/A | VT not reported |
| Su et al. [85] | China | Prospective cohort, single centre | Sepsis admission, ICU>24 hrs | Sepsis 58.8 (18.0); Non-sepsis group | M: 137 (51%) | Sepsis group: APACHE 19.0 (7.3) | Not significant differences in VT in sepsis and non-sepsis groups up to two years following ICU discharge |

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| | | | | 57.4 (17.5) | | SOFA 7.58 (3.1)<br>Non-sepsis group:<br>APACHE 14.8 (6.1)<br>SOFA 5.4 (3.4) | |
| Wittbrodt et al. [91] | Denmark | Cross-sectional, multicentre (sub-study of previously published RCT) | Severe sepsis in ICU and fluid resuscitated with Hydroxyethyl starch (HES) or Ringers lactate | HES: 66 (59-74)<br>Ringers lactate: 66 (58-75) | M: 105 (55%) | SAPS:<br>HES group: 48 (36-58)<br>Ringers group: 50 (38-59)<br>SOFA:<br>HES: 7(5-9)<br>Ringers: 7 (5-9) | Hydroxyethyl starch administration associated with lower VT scores compared with Ringer's lactate |
| Specialist | | | | | | | |
| Combes et al. [35] | France | Cross-sectional, single centre | Cardiogenic shock requiring ECMO | 46 (17) | M: 24 (71%) | SOFA: 13 (5)<br>SAPS II: 46 (13) | VT no worse than population norms, but worse physical and social problems |
| Roll et al. [76] | Australia | Prospective cohort, single centre | ICU patient requiring ECMO | 42 (26.5-57) | M: 19 (58%) | APACHE II: 20 (16-26.5) | VT not significantly reduced compared to matched norms at 12 months |
| ARDS | | | | | | | |
| Deja et al. [41] | Germany | Prospective cohort, Single centre | Severe ARDS | 39 (15) | M: 35 (54%) | APACHE II: 16 (6) | Lower VT scores compared with population norms |
| Herridge et al. [53] | Canada | Prospective cohort, Multicentre | ARDS | 45 (36-58) | M: 66 (56%) | APACHEII: 23 (17-27) | Patients with cognitive impairment after ARDS had worse HRQoL |
| Needham at al. [71] | USA | Prospective multicentre longitudinal follow up | Acute lung injury survivors on the EDEN trial followed up at 6 and 12 months | 52 (16) | M: 483 (51%) | APACHE III: 91 (27) | VT not reported |
| Rothenhäusler et al. [78] | Germany | Prospective cohort, single centre | ICU with ARDS (1994 definition) | 18-44yrs, 65.1%; 45-54yrs, 6.6%; | M: 24 (52%) | NR | Patients with cognitive impairment after ARDS had worse HRQoL |

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| | | | | 55-64yrs, 19.5%; >65yrs, 8.8% | | | |
| Unselected | | | | | | | |
| Choi et al. [8] | USA | Single centre, longitudinal cohort | Medical ICU survivors | 52.2 (15.6) | M: 19 (70%) | APACHE II: 21.6 (8) | VT not reported |
| Spadaro et al. [9] | Italy | Single centre, prospective cohort | ICU survivors at one year | 67.5 (59-74) | M: 38 (68%) | SAPS II: 31 (27-37)<br>4 (3-6) | VT not reported |
| Wintermann et al. [10] | Germany | Single centre, prospective cohort | ICU survivors with critical illness polyneuropathy/myopathy | 61.1 (55.7-65.6) | M: 82 (73%) | N/A | VT not reported |
| Aitken et al. [24] | Australia | Nested cohort study within RCT, multicentre | ICU >48 hrs and MV >24 hours | Group 1: 56 (16.4)<br>Group 2: 59 (15.2) Group 3: 57 (16.2) | M: 136 (70%) | APACHE II:<br>Improved 6MWD: 20.6 (12.4)<br>Not improved 6MWD: 18.0 (5.7)<br>Did not complete 6MWD: 17.7 (6.6) | Higher VT scores at 6 months associated with improved 6MWD |
| Bäckman et al. [25] | Sweden | Prospective, intervention cohort, single centre | ICU >72 hrs | Diary group: 50.7 (17.2)<br>No-diary group: 62.2 (17.8) | F: 152 (58%) | Diary group: 18.7 (7.3)<br>No-diary Group 2: 14.1 (6.5) | Higher VT scores at 6 and 36 months in patients given an ICU diary |
| Bocci et al. [30] | Italy | Single centre cohort | Trauma ICU (>48hrs) survivors | 38 (27-51) | M: 29 (91%) | ISS 29 (22-38)<br>SAPS II 32 (25-43) | VT not reported |
| Boyle et al. [31] | Australia | Prospective cohort, single centre | ICU >48 hours | 58.9 (14.7) | M: 42 (63%) | APACHE II: 16 (7.3) | Lower VT scores associated with development of chronic pain |
| Chaboyer et al. [32] | Australia | Prospective cohort, single centre | Not reported | 60.5 (18.2) | F: 11 (55%) | APACHE II: 12.5 (4.5) | VT scores lower than population norms; caution when using proxies |
| Colman et al. | Australia | Mixed Methods | Patients intubated >4 | 59 | M: 3 (60%) | APACHE II: 21 | VT not reported |

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| [34] | | | days. Median ICU length of stay 224 hours | | | (mean) | |
| Cuthbertson et al. [37] | UK | Prospective cohort, single centre | Expected to survive ICU | Median: 60.5 | M: 177 (59%) | APACHE II (median): 18 | Poor premorbid VT scores persist up to one year after ICU discharge |
| Cuthbertson et al. [38] | UK | Prospective cohort, single centre | Expected to survive ICU | 60.5 | M: 177 (59%) | APACHE II (median): 18 | Lower than population norm VT scores persist even up to 5 years after ICU discharge |
| Daffurn et al. [39] | Australia | Single centre, cohort | ICU survivors (>48 hrs ICU) | 51.27 (18.59) | More men than women | APACHE II: 17.36 (7.40) | VT not reported |
| Das Neves et al. [40] | Argentina | Single centre, prospective cohort | 112 ICU ventilated > 48 hours | 33 (24-49) | M: (68%) | APACHE II: 15+/-6 SOFA: 6+/-3 | VT not reported |
| Denehy et al. [42] | Australia | RCT, single centre | ICU stay >5 days | Usual care: 60.1 (15.8) Intervention: 61.4 (15.9) | M: 94 (63%) | APACHE II: Usual care: 20.7 (7.7) Intervention: 19 (6) | VT scores lower than population norms; no effect of an exercise intervention |
| Eddleston et al. [44] | UK | Prospective cohort, single centre | ICU survivors | 49 (11.5) | M: 75 (52%) | APACHE II: 18.7 (6.1) | Lower VT scores in females compared to males |
| Elliott et al. [45] | Australia | Prospective cohort, single centre | ICU > 24 hours | 56.1 (17.6) | M: 19 (56%) | APACHE II: 17 (7) | Survivors did not return to pre-ICU VT scores at 6 months |
| Elliott et al. [46] | Australia | RCT, multicentre | ICU >48 hours, received MV for at least 24 hours | Control: 57.5 (51.1) Intervention: 57.2 (17.0) | M: 113 (63%) | APACHE II: Control: 19.5 (7.2); Intervention: 19.4 (12.6) | Home-based exercise program did not improve VT scores |
| Elliott et al. [47] | Australia | A mixed-methods longitudinal single-centre pilot cohort | Survivors who had received invasive mechanical ventilation for at least 48 hours. ICU LOS 8.5 days | 62 | M: 13 (93%) | APACHE II: 21.7 (mean) | VT not reported |

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| | | study | (median) | | | | |
| Ferrand et al. [48] | France | Prospective cohort, single centre | ICU stay >48 hours | 63 (54-71) | M: 156 (71%) | SOFA: 4 (3-7) SAPS-II: 39 (30-48) | Age, prolonged MV, higher SAPS-II and ARDS associated with lower VT scores |
| Flaatten & Kvale [49] | Norway | Cross-sectional, single centre | ICU survivors still alive in 1999 | 33 (21.8) | M: 76 (72%) | APACHE II: 34.7 (17.4) | VT lower than population norms |
| Granja et al. [51] | Portugal | Cohort study (Part of a larger multicentre study) | 464 ICU survivors | 58 (43-69) | F: 183 (61%) | SAPS II: 31 (22-41) | No comparisons |
| Haines et al. [52] | Australia | Prospective cohort, multicentre | ICU stay >7 days | 64 (14.2) | M: 34 (61%) | APACHE II: 20 (7) | VT scores within standard deviation of normal at 5 years in Australian cohort |
| Hofhius et al. [55] | Netherlands | Prospective cohort, single centre | ICU >48 hours | 71 (62-77) | M: 451 (61%) | APACHE II: 19 (14-23) | HRQoL improves to age-specific norms at 5 years |
| Jeitziner et al. [57] | Switzerland | Prospective cohort, single centre | Age >65, ICU >48 hours | 68.7 (5.4) | M: 106 (63%) | APACHE II: 20.5 (8.5) | HRQoL lower in older survivors but remains stable at one-year post-ICU discharge |
| Kaarlola et al. [58] | Finland | Prospective cohort, single centre | ICU admission in 1995 | 57.8 (15.4) | M: 111 (66%) | APACHE II: 13.1 (7.3) | Gradual improvement in VT scores over time |
| Kelly & McKinley [61] | Australia | Cross-sectional, single centre | ICU >48 hrs | 60.4 (15.8) | M: 23 (59%) | APACHE II: 13.7 (7) | Small sample so comparison of VT not made |
| Khoudri et al. [62] | Morocco | Cross-sectional, single centre | ICU >24 hrs | 38.2 (17) | M: 79 (54%) | APACHE II: 14.1 (6) | Severity of Illness at ICU admission significantly associated with lower VT |
| Kowalik et al. [64] | Poland | Before-and-after cohort, single centre | OHCA +/- mild therapeutic hypothermia | Control: 59.4 (2.9) Study group: 55.56 (2.8) | M: 22 (71%) | NR | Mild therapeutic hypothermia after OHCA associated with higher VT scores |
| Kress et al. [65] | USA | RCT, single centre | ICU>24hrs | Control 47.2: (20.2) Study | F: 22 (65%) | APACHE II: Control: 18.4 | Sedation interruptions had no significant impact on VT |

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| | | | | group: 49.5 (15.8) | | (6.8)<br>Study group: 16.2 (5.7) | |
| Kvale & Flaaten [66] | Norway | Prospective cohort, single centre | ICU >24hrs | 51.9 (16.4) | M: 60 (60%) | SAPS II: 36.7 (13.4) | Moderate improvement of VT between 6 months and 2 years |
| Langerud et al. [68] | Norway | Longitudinal cohort two centre | ICU > 48 hours | 55.1 (14.4) | M: 64% | SAPS II: 44.9 (SD16)<br>SOFA: 8.8 (SD 3.4) | VT not measured |
| Lasocki et al. [69] | France | Prospective multicentre observational | Anaemic ICU patients in hospital for >5 days | 63 (48-73) | M: 77% | SAPS II: 52 +/-25<br>SOFA: 9+/-5 | VT not measured |
| Maley et al. [70] | USA | Two centre mixed methods pilot study | Survivors with ICU LOS at least 2 days. ICU LOS 5.1 (2.5–11.3) days | 59 (+/-15) | F: 25 (58%) | Not reported | VT not measured |
| Orwelius et al. [73] | Sweden | Prospective cohort, multicentre | ICU >24 hrs | 58.8 (17) | M: 274 (57%) | APACHE II: 15.3 (7.2) | Pre-existing co-morbidities influence long term HRQoL including VT |
| Raggi et al. [75] | Canada | Single centre, cohort | Post Heart-lung transplant patients (3.5 years after transplant) | 56 (10.4) | F: 24 (55%) | APACHE II: 22 (4.7) | VT not measured |
| Schandl et al. [79] | Sweden | Prospective cohort, single centre | ICU >96 hrs | 52.6 (17.8) | M: 36 (61%) | APACHE II: 21.4 (9.1) | Showed improvement over time especially between 3 and 6 months |
| Schniederman [80] | South Africa | Prospective cohort, single centre | ICU>24 hrs with MV | 36.9 (12.7) | M:23 (82%) | APACHE II: 17 (7.7) | No significant relationship between type of trauma or sex and VT |
| Skinner et al. [81] | Australia and New Zealand | Prospective cohort, multicentre | ICU with H1N1 requiring MV | 42 (29-53) | F: 32 (52%) | APACHE II: 18 (14-20) | VT at 6 months similar to matched ICU patients without H1N1, returned to healthy matched patient after one year |
| Steenbergen et al. [82] | Netherlands | Retrospective cohort, single centre | ICU survivors (>72hrs ICU) | 68 (58-75.3) | M: 273 (62%) | APACHE II: 14.4 (4.1-38.3)<br>SOFA: 8 (6-10) | VT scores lower than population matched norms |

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| Stricker et al. [84] | Switzerland | Prospective cohort, single centre | ICU patients | ICU stay <7days: 59 (47-68)<br>ICU>7 days: 67 (53-72) | M: 105 (70%) | SAPS II:<br>ICU stay >7days: 36 (29-42)<br>ICU stay <7days: 34 (28-40) | VT not significantly different between long and short stay patients |
| Svenningsen et al. [86] | Denmark | Prospective cohort, single centre | ICU>48hrs | 61 (15) | M: 204 (57%) | SAPS II: 38 (16) | VT score not significantly different between patients with delirium and those without delirium. |
| Van den Boogard et al. [87] | Netherlands | Cross-sectional, single centre | ICU>24hrs | 65 (57-72) | M: 69 (67%) | APACHE II: 14 (11-17) | Overall HRQoL similar in patients with delirium to adjusted patients. |
| Van Vliet et al. [88] | Netherlands | Cross-sectional, single centre | Patients with haematological malignancy | Haematology with ICU: 52.8 (14.2)<br>Haematology without ICU: 53.5 (13.3)<br>General ICU: 56.9 (16.7) | M: 143 (53%) | APACHE II:<br>Haematology and ICU: 18.5 (9.2);<br>General ICU: 19 (5.4) | No significant difference in VT between patients with haematological malignancy and those without |
| Walsh et al. [90] | Scotland | Two centre RCT | ICU survivors >48 hours ventilation | 62 (51-51) | M: 147 (57%) | APACHE II: 19 (15-26) | VT not reported |
| Zaheri et al. [92] | Iran | Cross-sectional, single centre | ICU>24 hours | 54 (16.1) | M: 185 (57%) | NR | The quality of life scores of patients discharged from ICU is low. Age, drug abuse, long-term hospitalisation, mechanical ventilation, and post-traumatic stress disorder are risk factors that decrease quality of life. |
| Zhang et al. [93] | China | Case-control, multicentre | ICU>24 hours | Sepsis group: 53.1 (17.3)<br>Non sepsis: 47 (18.2) | M: 55 (73%) | APACHE II: Sepsis: 18.3 (6.8) Non sepsis: 13.7 (6.5)<br>SOFA: Sepsis 5.9 (3.5) Non sepsis 4.4 (2.0) | VT significantly lower in survivors of severe sepsis |

M, Male; SAPS, Simplified Acute Physiology Score; VT, vitality; RCT, randomised controlled trial; NR, not reported; ISS, injury severity score; LOS, length of

stay; APACHE, Acute Physiology and Chronic Health Evaluation; F, female; MV, mechanical ventilation; SOFA, Sequential Organ Failure Assessment ARDS, Acute Respiratory Distress Syndrome; ECMO, Extracorporeal Membrane Oxygenation; ICU, Intensive Care Unit; HRQoL, Health-related quality of life; 6MWD, six minute walk distance; OHCA, out of hospital cardiac arrest; SIRS, systemic inflammatory response syndrome

**Supplementary Table 3** Study characteristics of included qualitative studies

| Author (s) | Study design | Country/Unit | Aim | Sample | Data collection | Data |
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| Ågård et al. [22] | Multi-centre qualitative longitudinal grounded theory study | Denmark<br><br>5 ICUs in 3 hospitals: 4 general, 1 neurosurgical | To explore the challenges facing ICU survivors with a cohabiting spouse or partner and explain patients' concerns and coping modalities during the first 12 months post ICU discharge. | 18 patients of working age (intubated for >96 hours) and their cohabiting partner<br><br>11 male, 7 female<br><br>Age 35-70, (mean 55)<br><br>Time since discharge 3-14 months<br><br>ICU LOS 5-74 days | Semi-structured dyad interviews at 3 & 12 months post ICU discharge (60-90 minutes)<br><br>X 2 patient only focus groups at 3-12 months post ICU discharge (n=3, n=7)<br><br>X2 partner focus groups at 3-12 months post ICU discharge: (n=2, n=7) | The majority had experienced weight loss, fatigue, and loss of appetite. During the first months after ICU discharge, the training activities combined with frequent hospital appointments often entailed a tight schedule for the patients leaving little energy for other activities such as interaction with friends and family during the week.<br><br>*"Then I had to try to get up with a walker and I just couldn't. I couldn't even hold my head. I wasn't able to do anything."*<br>(ID no. 14, male, 67 years)<br><br>*"I felt it took forever before I regained my strength. I just deposited my physical strength at the hospital and I still feel it. I mean, I don't feel I am up to my usual strength yet. I need an afternoon nap, sometimes two. I feel that I need more strength to open the lid of a jar of jam. I was actually quite strong before I got sick."*<br>(ID no. 15, male, 68 years)<br><br>*"In the beginning when I came home and wanted to go upstairs, I sat on my behind and went up and down the stairs. It took a while before I could get around."*<br>(ID no. 6, female, 45 years)<br><br>*"I probably went too far. I mean, I was at home and tried to arrange that my husband didn't need to come home and do things. But then I was tired and couldn't* |

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| | | | | | | *handle it anyway."*<br>(ID no. 2, female, 40 years)<br><br>*"You know what, I don't want to go home and have my wife help me get to bed and help me go to the bathroom*<br>*— and if I fall — I just don't want to be a burden to her.*<br>*That's it! When I can walk again it will be different."*<br>(ID no. 13, male, 64 years, at three months) |
| Choi et al. [33] | Single-centre qualitative study-secondary analysis of interview data from a parent study | USA<br><br>Medical ICU | To describe challenges and needs of family caregivers of ICU survivors related to patients' home discharge. | 20 carers of patients who had been ventilated for at least 4 days in an ICU.<br><br>16 women and 4 men<br><br>Aged 24-71 (mean 52 yrs)<br><br>12 spouses<br><br>All white<br><br>ICU length of stay 5–39 days | Semi-structured interviews, face to face (1 by telephone) at 3 time points during the post ICU discharge period:<br>-2 weeks<br>-2 months<br>-4 months | **Normal part of recovery**<br>Family caregivers did not view symptoms, such as fatigue and pain as life threatening but considered them an indicator of incomplete recovery. *"No one seems to know how long his condition is going to be the way it is or if it is ever going to be any different, if he's ever going to get better, or if he's just going to stay the same."* (Interviewed > 2 months post-home discharge)<br>**Pacing**<br>*"This has been really hard because there's no one to one correlation with what he does and how he feels. Like he can go out and do something one day, feel pretty good, but then 2 days later he'll be really tired. No one can tell us how to increase that activity level appropriately; it's really just trial and error, so it's a little frustrating*." (Interviewed > 2 months post-home discharge)<br>**Caregiver fatigue**<br>*"It seems I'm worse tired now than I was when she was sick and right out the hospital. I don't know whether it's just catching up with me or not, but I'm mentally and emotionally exhausted ... Everything just seems like a struggle lately."* (Interviewed at > 2 months post-home discharge)<br>*"I would do what the doctors told me to do in the first* |

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| | | | | | | *place and go home and rest while he was in the hospital. I think I drained myself a lot. I think my health went downhill a lot when he was sick ... But I think looking back, in retrospect, I should have."* (Interviewed at > 2 months post-home discharge) |
| Colman et al. [34] | Mixed Methods study including a qualitative phenomenological component | Australia | To explore the experiences of fatigue in survivors of critical illness a year or more post ICU discharge | Five patients (mean age 59 years) intubated for more than 4 days<br><br>3 males and 2 females<br><br>median APACHE II score of 21<br><br>median length of time between hospital discharge and interview was 29 months<br><br>median ICU length of stay was 224 hours | Semi-structured face to face interviews at least 1 year post ICU discharge. | Participants described four key themes relating to their experiences of fatigue post critical illness: (1) multifaceted fatigue; (2) lack of information; (3) strategy formation; and (4) role loss.<br><br>Participants reported that **cognitive dysfunction** was often long lasting, ranging from three months to more than two years in duration, and impacted on them in both social and working domains. They reported difficulty with concentration, memory and processing, all of which worsened with increased fatigue. These difficulties were illustrated by one participant, Belinda, who said;<br><br>"*He [co-worker] was just throwing all these questions at me and it was really challenging for me because I struggled to follow the conversation let alone be able to answer it and to remember. There were all these challenges thrown at me across different ways… like processing conversation and listening to what he's saying and following it."* (XXXB)<br><br>Participants commented that within the first three months they had reduced ability to perform activities such as housework, lawn mowing, car washing, and even basic tasks such as showering.<br>*"The fatigue when I first came out of hospital was just really overwhelming and something that you just think, wow, you know walking from your bedroom to your kitchen and back you're exhausted."* (XXXB) |

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| | | | | | | Three out of five participants saw their fatigue as **something that was a natural consequence of their illness** experience, and therefore not something to be concerned about;<br>*"I don't think of it as fatigue, I just think of it as getting over what I've been through*" (XXXR)<br>*"You just assume that's the way it is. Well I do anyway. You're tired because you were crook [unwell]"* (XXXR).<br><br>**Impacts**<br>Parenting role; *"Being a Mum I was always the one who would get up early, get my kids ready for school, pack their lunch, do their uniform, and get them off… After hospital, I found it extremely fatiguing to just… to get up, to walk down the hall, to put the iron board up, to plug the iron in, to iron the clothes. That was just exhausting."* (XXXB)<br><br>Working & finance:<br>XXXB felt that *"the cognitive processing I needed for the type of work that I do was just so far beyond me."*<br><br>*"Financially, I'd lost the business, we had to close it, so we were in debt to the bank on that one. We had no money coming in, we couldn't pay the mortgage…. Just all those money worries, you know. The severe money worries."* (XXXR)<br><br>Social & relationships:<br>*"I would think, oh, I wish this was over. I want to go home and have a sleep" (*XXXR)<br><br>"*That was something that I really noticed that I wasn't able to do, things like laughing and being humorous would just fall off as something that's not really important when you're trying to do the basics of* |

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| | | | | | | *having a conversation."* (XXXB)<br><br>B said *"for what is now my ex-husband, at the time, I didn't realise it, but he just didn't cope with not being paid attention to."*<br><br>**Management**<br>Strategies included sleeping, regular exercise and routine, diet changes, avoidance and pacing.<br><br>**Sleeping** "*the best and most important thing you can do for yourself that doesn't cost you a thing"* (XXXB).<br><br>**Exercise** (2/5);<br>*"any tiredness I had after that I felt was a natural tiredness, not just a tiredness from being unwell*" (XXXRh).<br><br>**Avoidance**<br>3/5 Avoided conversations and social interactions:<br>*"I got very good at saying no"* (XXXRh)<br><br>*"I just had a strategy to say, I'm actually just not even going to ask anything, because I can't handle it if people say stuff"* (XXXB).<br><br>**Pacing;**<br>*"That whole philosophy of how do you eat an elephant? One bite at a time. I'd always just think, ok, I'm just going to take that bite. I'm just going to do that, and then finish this bit. And I took that same philosophy across to recovering where I would just go, well, this is what I've got and now I'm just going to deal with this. I'm just… putting one foot in front of the other*." (XXXB) |

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| | | | | | | I**nfo and support;**<br>*"I should have been sent to see… somebody to help… to sort of tell you what was going to happen and what to expect to happen. That sort of stuff. 'Cause you get nothing out of the doctors or the nurses, you know. They just tell you 'ok, you're good enough to go, away you go.'"* (XXXR)<br><br>*"Nobody forewarned us about anything…. Even if a doctor sat you down and said to you 'you can expect to be very tired for the next two years. You're going to get fatigue. This is going to happen to you, that is going to happen to you. Expect this'".* (XXXRo)<br><br>*"The fatigue part of it has never been broached. Never"* (XXXR). |
| Eakin et al. [43] | Multi-centre qualitative study from 41 hospitals | USA | To describe the survivorship experience of patients who had acute respiratory failure. | 48 patients<br><br>(mean age 53 years, 26 females)<br><br>39 Caucasian<br><br>APACHE II 100 (mean)<br><br>ICU LOS 13 days (mean)<br><br>Being followed up longitudinally as part of the ARDS Network Long-term Outcomes Study (ALTOS) and the Recovery | 30 minute semi-structured 1-1 telephone interviews 5-18 months after the start of mechanical ventilation | Survivors described increased fatigue and major impairments to their stamina and sleep habits:<br><br>*"I used to have to lie down for at least an hour in the middle of the day and now if I can grab 15 or 20 minutes and put my feet up I can recover and go on".* (Female, 62 years old, 7 months after mechanical ventilation)<br><br>*"I take naps like 2 hours a day every day, and if I don't, I'm wiped out".* (Male, 46 years old, 12 months after mechanical ventilation)<br><br>*"I can't wait until the afternoon to exercise or I'd be too tired."*<br><br>*"If I do more than the routine, I have to stop and think about okay, you know, this is making me tired, I am losing my breath".* (Female, 71 years old, 5 months after mechanical ventilation) |

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| | | | | of Muscle After ARF (ROMA) study. | | *"Well I'm cooking more. I don't really do any like housework or anything like that, but I could like straighten up my bathroom you know, I could do that, stuff like that. I fold clothes. I don't wash them."* (Female, 60 years old, 6 months after mechanical ventilation)<br><br>*"I've decreased the activities I do, mainly because of both financial and energy level. I used to do more active things with my down time. . . And nowadays, you know it's just pretty much me relaxing and trying to keep calm".* (Male, 34 years old, 12 months after mechanical ventilation) |
| Elliott et al. [47] | A mixed-methods longitudinal single-centre pilot cohort study with embedded interviews | Australia<br><br>58 bedded ICU with two general medical-surgical ICUs, one cardiothoracic and one neurosurgical. | To test the feasibility of a study protocol designed to ascertain the incidence and impact of cognitive impairment during recovery from a critical illness. | 14 Patients who had received invasive mechanical ventilation for at least 48 hours<br><br>Mean age 62 years, 13 men<br><br>APACHE II: 21.7 (mean)<br><br>ICU LOS 8.5 (median) | Semi-structured interviews (2-14 minutes) at 2 and 6 months (*n*=11) post ICU discharge | At two months the prevalent theme was fatigue:<br>*"Well fatigue is the main thing that is affecting my life in that I do not have the stamina to do what I do in my normal life even simple tasks I would not even thought twice about like walking around the block. I find it exhausting."* (#7, two months)<br><br>*"I just can't, I've got no energy to do anything. I have trouble. I can't walk very far. I've just got no energy. I've got no strength on my arms. I can't even open a bottle of drink without help*." (#20, two months)<br><br>*"I did slow down a bit and lost my fitness physical fitness ... which I am now slowly regaining. But it is a bit of an effort. I try to walk every morning and I do gardening."* (#3, six months)<br><br>*"I was stunned at the drop in physical fitness. I am similarly stunned at the time it's taken to get to the point where I am at. I thought I would be here much quicker. I am disappointed to be told that it will take a fairly long time and measured in [several] months not* |

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| | | | | | | *weeks."* (#7, two months)<br><br>**Cognitive fatigue**<br>As participants perhaps became less concerned about physical<br>symptoms, they were more aware of their "cognitive fatigue" and<br>some volunteered strategies to deal with this, such as the use of<br>reminders in calendars, Sudoku and pacing activity levels:<br><br>"*When you are tired you don't want to blooming think, you just want to go with the flow."* (#10, two months)<br><br>*"But you know I think that definitely helps ... when I play it [Sudoku] and the time it takes for me to do it is all related to the fatigue factor and the concentration factor so if I am fatigued it takes forever to do it and I just have to put it down."* (#21, six months)<br><br>"*I do have to write on the calendar. So I write everything down so that I am doing something every day this week. Sometimes 2 or 3 like I am going to the taxman, yesterday and the day before I was doing things. But I had the whole week planned in the beginning and I had to write it all down to make sure I knew exactly what I was doing. Tomorrow the car is going in for service, today you were coming and get down to the taxman."* (#13, six months) |
| Kang & Jeong [59] | Multi-centre grounded theory study | South Korea<br><br>Four medical, surgical & cardiac ICUs | To explore critical care survivors' experience of post-intensive care syndrome. | 13 Patients admitted for more than 48 hours | Semi structured interviews 1-3 times (45–124 min per interview). | The physical impairment described by current participants included complex symptoms such as pain, fatigue and activity reduction rather than simple muscle weakness. |

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| | | | | Aged 20-72 (mean 52 years)<br><br>7 men and 6 women<br><br>ICU stay 3-50 days | 16 interviews<br><br>Face to face but one done by email<br><br>Data collected 1 month to 9 years after hospital discharge | *"I get easily tired. I can only do one thing a day. If I had two appointments, I couldn't make it because I would be exhausted even before I finished the first one. I cannot move as much as I did before... I feel so close to memory a long time ago; but, I cannot remember what happened just yesterday... Now I feel a bit timid and passive compared to the past... When I go outside, I feel like I cannot go well".* (Participant 4)<br><br>*" did not have any energy after I left the hospital. I have changed a lot from the past. I used to be the breadwinner; but, now, I need the full help of my wife. I am so sorry for my wife... I used to think that I could do anything before; but, now I wonder what I can do. I wanted to volunteer and do activities against the nuclear power plant... In reality, it is not easy for me to go out to meet friends now. . . I do not want to go out. I am not even confident to meet new people*."<br>(Participant 7)<br><br>*"These days, my brother has to be at home with me because I do not have any strength in my arms and legs. Once I went to the bathroom, my legs got stuck and I fell down... I hardly get out of my house by myself. I was married; but, I've got (ten) separated. I have spent many years in the hospital and my economic situation got worse and worse... All of these situations are stressful. . ."*<br>(Participant 13)<br><br>*"I used to think 'What's the big deal? There is nothing I can't do!' But, now, I go 'I might not do it'. But, even if I cannot, it is not that great. I can go slow. Getting back on the road is not a big deal."*<br>(Participant 12) |
| König et al. | Interview study | Germany | To understand how | 15 sepsis | Face to face or | Eleven domains emerged as critically important: |

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| [63] | and a modified Delphi process | Interdisciplinary ICUs | HRQoL is perceived by sepsis survivors. | survivors 6-36 months post diagnosis<br><br>At least 2 days in ICU<br><br>Mean age 62 years (27-87)<br><br>8 men, 7 women | telephone interviews length (34–95 mins)<br><br>Time from sepsis to data collection 5-40 months | Psychological impairment; fatigue; physical impairment; coping with daily life; return to normal living; ability to walk; cognitive impairment; self-perception; control over one's life; family support; and delivery of health care.<br><br>Fatigue (defined as 'Lack of motivation, weakness, and the feeling of weakness') received from consensus from patients and family members.<br><br>Survivors described a lack of motivation to do something, a general feeling of listlessness (not caused by muscle weakness). Many days, they are unable to do anything and feel passive all the time:<br>*"I was just sitting there and waited and waited... until it was 12 o'clock again... that he [the nurse] would come back. And give me the injection and prepare some food. And then I was waiting again for the next meal.'* – (Female, 78 years, 12 months after sepsis due to an infected gallbladder. This elderly lady experienced severe fatigue. With time she overcame her lethargy, regained physical strength and is again living independently. She does not want to be a nursing case ever again.) |
| Maley et al. [70] | Two centre mixed methods pilot study | USA<br><br>36 bedded Medical ICU | To examine the association between resilience and neuropsychological and physical function<br><br>To contextualize these findings within the survivors' recovery experience. | 43 survivors with an ICU length of stay of at least 2 days<br><br>Mean age 59 years (+/-15)<br>18 men, 25 women<br>14 white, 25 black<br>ICU LOS 5.1 (2.5–11.3) days | Telephone interviews (approx. 30 mins) using a questionnaire, which allowed free text verbal responses<br><br>5-12 months post hospitalisation | "*Feeling weak. I didn't even have the strength to feed myself."* (on ward)<br><br>"*Doing everyday things [at home] was hard without help constantly there."*<br><br>"*Everything was a challenge. I had no strength to do anything."* |

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| Strahan et al. [83] | Single centre phenomenological study | Northern Ireland<br><br>Mixed ICU (for major trauma, neurosurgery, thoracic, vascular, spinal, orthopaedic surgery patients and patients with severe burns). | To explore and describe the lived experiences of patients following transfer from the intensive care unit | 10 patients in ICU for longer than 3 days<br><br>Age 18-77 years<br><br>7 men, 3 women | Open ended interviews (15-35 mins) conducted on ward 3-5 days post ICU discharge | Authors highlight fatigue:<br>In 'Description of lived experience': Physical response reveals a multiplicity of difficulties experienced by patients including sleep disturbances, digestion and mobility. Fatigue and weakness are prevalent.<br>In 'Essential structure of the lived experience': In the immediate post transfer period (from ICU to ward) there is an overwhelming feeling of weakness and fatigue. This can be compounded by experiences of sleep disturbance, including nightmares.<br><br>Under 'Theme Category A: Physical Response', Fatigue is one identified theme listed under the theme cluster 'Mobility' with patient quotes:<br><br>Jane: *''I can't go for a shower myself, somebody has to take me for a shower and that exhausts me, but hopefully in another few days I will get there''*.<br><br>John*: ''I am tired all the time''*.<br><br>Robert: *''I feel very weak''*. |

APACHE, Acute Physiology and Chronic Health Evaluation; ARDS, Acute Respiratory Distress Syndrome; ARF, Acute Respiratory Failure; HRQOL, health-related quality of life; ICU, Intensive Care Unit; LOS, length of stay;

**Supplementary Table 4** Follow up methods, duration of follow-up and response rates. Values are number (proportion).

| Reference | Method of assessment | Response rate | Control group | Follow-up period |
|---|---|---|---|---|
| Choi et al. [8] | Face to face | 27/47 (57%) | NR | 4 months |
| Spadaro et al. [9] | Face to face | 56/115 (49%) | NR | 12 months |
| Wintermann et al. [10] | Telephone | 113/195 (58%) | NR | 3 and 6 months |
| Abelha et al. [21] | Postal | 226/294 (77%) | No control group | 6 months |

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| Agren et al. [22] | Telephone and face-to-face | 33/42 (79%) | Control arm of RCT | Baseline, 3 and 12 months |
| Aitken et al. [24] | Face-to-face | 145/195 (74%) | Control arm of RCT | Baseline, 1 week, 2 and 6 months |
| Bäckman et al. [25] | Postal | 262/761 (34%) | No diary group | 6, 12, 24 and 36 months |
| Bakhru et al. [26] | Face-to-face | 30/36 (83%) | No control group | 1 month |
| Bapat et al. [27] | Telephone | 60/60 (100%) | Uncomplicated postoperative course | 12 months |
| Baranyi et al. [28] | Postal | 126/215 (59%) | Healthy controls | ~24 months |
| Battle et al. [29] | Postal | 50/69 (72%) | Population matched norms | 6-12 months |
| Bocci et al. [30] | Face to face | 32/38 (84%) | NR | 12-24 months |
| Boyle et al. [31] | Postal | 66/99 (67%) | Population matched norms | 1 and 6 months |
| Chaboyer et al. [32] | Postal | 16/20 (80%) | Population matched norms | ICU discharge, 6 and 12 months |
| Colman et al. [34] | Unclear | 5/5 (100%) | NR | 29 months |
| Combes et al. [35] | Telephone | 28/34 (82%) | Population matched norms | ~11 months (median) |
| Contou et al. [36] | Telephone | 37/78 (47%) | Septic shock without purpura fulminans | ~55 months |
| Cuthbertson et al. [37] | Telephone | 172/300 (58%) | Population matched norms | 3, 6 and 12 months |
| Cuthbertson et al. [38] | Telephone | 105/300 (35%) | Population matched norms | 2.5, 5 years |
| Daffurn et al. [39] | Face to face | 54/54 (100%) | NR | 3 months |
| Das Neves et al. [40] | Face to face and Telephone | 76/12 (68%) | NR | 1, 3, 6 and 12 months |
| Deja et al. [41] | Postal and telephone | 65/129 (50%) | Population matched norms | ~57 months |

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| Denehy et al. [42] | Unclear | 82/150 (55%) | Control arm in RCT | 12 months |
| Eddleston et al. [44] | Face-to-face | 136/143 (95%) | Population matched norms | 12 months |
| Elliott et al. [45] | Postal and telephone | 19/34 (56%) | Population matched norms | 6 months |
| Elliott et al. [46] | Face-to-face | 161/195 (82.5%) | Control arm in RCT | 1 week, 2 and 6 months |
| Elliott et al. [47] | Telephone and face to face | 11/14 (76%) | NR | 2 and 6 months |
| Ferrand et al. [48] | Telephone | 198/220 (90%) | NR | 3 and 6 months |
| Flaatten & Kväle [49] | Postal | 51/88 (58%) | Population matched norms | 12 years |
| Fu et al. [50] | Telephone | 347/347 (100%) | Not reported | 12 and 24 months |
| Granja et al. [51] | Postal | 464/909 (51%) | No control group | 6 months |
| Haines et al. [52] | Telephone | 56/68 (82%) | Population matched norms | 1 and 5 years |
| Herridge et al. [53] | Face-to-face | 83/97 (86%) | Healthy controls | 3, 6 and 12 months |
| Heyland et al. [54] | Telephone | 30/39 (77%) | Population matched norms | ~16 months (mean) |
| Hofhius et al. [55] | Telephone and face-to-face | 95/95 (100%) | Population matched norms | ICU discharge, hospital discharge, 3 and 6 months |
| Jeitziner et al. [57] | Telephone | Unclear | Age-matched comparator group | 1 week post-ICU, 6 and 12 months |
| Kaarlola et al. [58] | Postal | 192/252 (76%) | Population matched norms | 1 and 6 years |
| Kayumba et al. [60] | Postal | 50/50 (100%) | Control arm of RCT | 6 months |
| Kelly & McKinley [61] | Telephone and face-to-face | 39/141 (28%) | Population matched norms | 1-6 months after ICU discharge |

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| Khoudri et al. [62] | Telephone and face-to-face | 145/311 (47%) | NR | 3 months |
| Kowalik et al. [64] | Telephone and face-to-face | 31/39 (80%) | Admitted with OHCA between 2009-2011 | ~9 months intervention, ~45 months control |
| Kress et al. [65] | Face-to-face | 32/105 (30%) | Control arm in RCT | 6 months |
| Kvale & Flaaten [66] | Postal | 126/226 (56%) | NR | 6 months and 2 years |
| Lagercrantz et al. [67] | Postal | 60/141 (42%) | Age and gender matched population norms | NR |
| Langerud et al. [68] | Not stated | 118/193 (61%) | NR | 3 and 12 months |
| Lasocki et al. [69] | Telephone | 80/113 (71%) | NR | 28 days and 6 months |
| Needham et al. [71] | Telephone and postal | 514/525 (98%) | NR | 6 and 12 months |
| Nesseler et al. [72] | Postal | 39/93 (42%) | Population matched norms | 6 months |
| Orwelius et al. [73] | Postal and telephone | 980/1663 (59%) | Population matched norms | 6, 12, 24 and 36 months |
| Pettilä et al. [74] | Postal | 307/354 (87%) | Population matched norms | 12 months |
| Raggi et al. [75] | Postal (with phone reminder) | 44/61 (72%) | NR | >12 months |
| Roll et al. [76] | Postal and telephone | 33/47 (70%) | Age and gender matched controls | 12 months |
| Rosendhal et al. [77] | Postal | Unclear | NR | 55 months (average) |
| Rothenhäusler et al. [78] | Face-to-face | 46/119 (39%) | Age and gender matched controls | 6 years |
| Schandl et al. [79] | Face-to-face | 26/92 (29%) | NR | 3, 6 and 12 months |
| Schniederman [80] | Face-to-face | 28/32 (88%) | NR | 6 months |
| Skinner et al. [81] | Telephone | 44/75 (59%) | ICU patients without H1N1 and population matched norms | 6 and 12 months |

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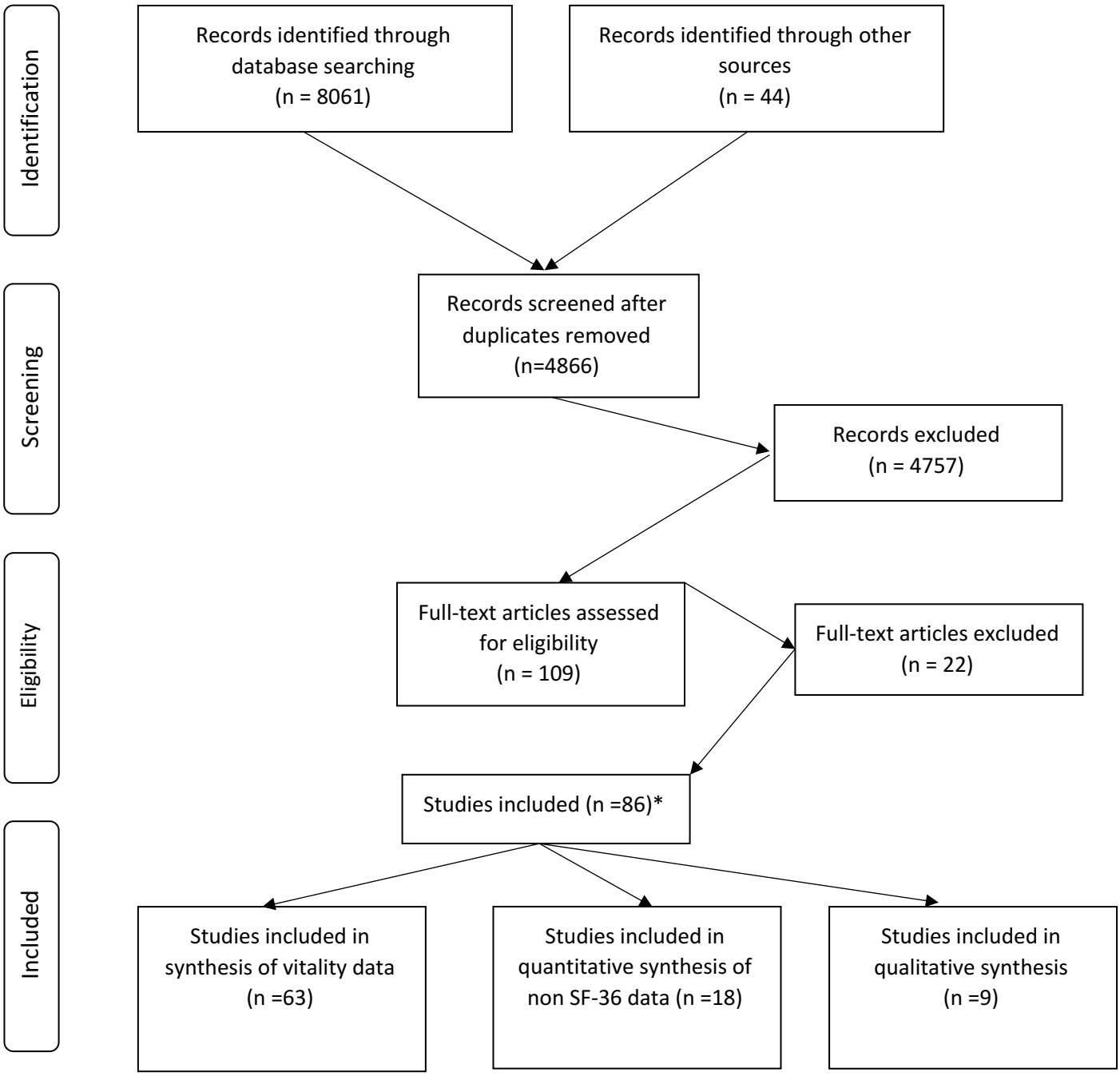
| Steenbergen et al. [82] | Postal | 191/740 (26%) | Population matched norms | 12, 24 and 36 months |
| Stricker et al. [84] | NR | NR | Matched to short stay patient based on diagnostic criteria and illness severity | NR |
| Su et al. [85] | Not reported | Sepsis: 14%<br>Non-sepsis: 26% | Non-sepsis | 3, 12 and 24 months after ICU discharge |
| Svenningsen et al. [86] | Face-to-face | 360/641 (56%) | NR | 2 and 6 months |
| Van den Boogard et al. [87] | Postal | 915/1292 (71%) | NR | Median 18 months |
| Van Vliet et al. [88] | Postal | 79% | Population matched norms | Median 16 months |
| Vogel et al. [89] | Postal | NR | Age and gender matched population norms | 3, 6 and 12 months |
| Walsh et al. [90] | Face to face and telephone | 228/240 (95%) | NR | 3, 6 and 12 months |
| Wittbrodt et al. [91] | Postal | NR | NR | 90 days |
| Zaheri et al. [92] | Postal and face-to-face | 325/342 (95%) | NR | 1 month |
| Zhang et al. [93] | Face-to-face | 75/224 (33%) | Population matched norms | 12 months |

NR, Not reported; RCT, Randomised controlled trial; ICU, Intensive care unit;

Figure 1: PRISMA diagram




*Some studies included data relevant to more than one synthesis approach