

Review Article

Changes in health-related quality of life after discharge from an intensive care unit: a systematic review

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Summary

Quality of life after critical illness is becoming increasingly important as survival improves. Various measures have been used to study the quality of life of patients discharged from intensive care. We systematically reviewed validated measures of quality of life and their results. We searched PubMed, CENTRAL, CINAHL, Web of Science and Open Grey for studies of quality of life, measured after discharge from intensive care. We categorised studied populations as: general; restricted to level-3 care or critical care beyond 5 days; and septic patients. We included quality of life measured at any time after hospital discharge. We identified 48 studies. Thirty-one studies used the **Medical Outcomes Study 36-Item Short Form Health Survey (SF-36)** and 19 used the **EuroQol-5D (EQ-5D)**; eight used both and nine used alternative validated measures. Follow-up rates ranged from 26–100%. **Quality of life** after critical care was **worse** than for age- and sex-matched populations. Quality of life **improved for one year** after hospital discharge. The aspects of life that improved most were **physical function, physical role, vitality and social function**. However, these domains were also the **least likely to recover to population norms** as they were more profoundly affected by critical illness.

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Introduction

Critical illness cared for on an intensive care unit (ICU) imposes a high treatment burden on patients and is an economic burden for the healthcare provider. The short-term survival of patients admitted to ICUs is well documented through comparative audit systems, such as the UK Intensive Care National Audit and Research Centre (**ICNARC**) Case Mix Programme [1] or the Australia and New Zealand Intensive Care Society (**ANZICS**) **CORE system** in **Australasia, Oman, India** and **Hong Kong** [2]. There is increased interest in studying and quantifying the quality of life of patients as survival after critical illness improves [3]. For survivors, the effects of critical illness persist long after hospital discharge. However, health-related quality of life (**HRQoL**) data after hospital discharge are not routinely

collected on a scale comparable to the national audit programmes. Comparison of these studies is difficult as different measurement tools and assessment times are used. For patients and the healthcare workers advising them, data on quality of life after critical illness informs discussions about treatment choices and expectations. Academics and policymakers need reliable data on quality of life to determine the economic burden of the treatment and long-term survival following critical illness.

Previous systematic **reviews** on this topic [4–10] included studies that are now well **over 15 years old**, when **quality of life was new to ICU outcome research**. Existing reviews have systematically examined changes in quality of life after discharge from an ICU. Only limited information on the time course of summary measures has been presented.

Many studies used their own (non-validated) measures that are difficult to compare [5, 6]. Studies have reported reduced quality of life after discharge from an ICU compared with the general population, and poor participant retention.

We undertook a systematic review of studies published after 1999 that investigated health-related quality of life in patients discharged from an ICU. Our aims were to identify the instruments used and to provide a synthesis of data on changes in quality of life after hospital discharge. We have looked for trends in the data, in contrast with previous narrative studies that might have missed some of the nuances of the existing research.

Methods

Our prospectively registered protocol followed the PRISMA guidelines for systematic reviews [11, 12]. In brief, we searched PubMed, CENTRAL, CINAHL, the Web of Science and Open Grey for studies of health-related quality of life (HRQoL) after discharge from an ICU, published in any language from January 2000 to January 2018. Our search terms were: ('quality of life' OR 'qaly' OR 'health-related quality of life') AND ('intensive care' OR 'icu' OR 'critical care' OR 'itu' OR 'intensive treatment unit' OR 'intensive therapy unit'). We searched title, abstracts and key words using MeSH terms where applicable.

We included prospective cohort studies, retrospective cohort studies, case-control studies, cross-sectional studies and randomised controlled trials (from which we used data from the control group). We restricted included studies to: adults (≥ 16 years); discharged from a general ICU after the year 1999; and quality of life assessments with a validated scale more than 3 months after hospital discharge, for the total cohort or sub-groups of interest. We did not include studies of a population restricted by age (other than children), disease or category of outcome or uncontrolled interventional studies. One author (AG) extracted study data, which included: study purpose; inclusion and exclusion criteria; number of participants; assessment tools, times, mode and measurements; attrition; sepsis definition; and author competing interests. Two other authors (DY or PW) were consulted to clarify data. We combined quality of life scores for sub-groups if reported in sufficient detail. We used the Newcastle-Ottawa scale to assess study methodological quality, which generates an aggregate score of 0–8 [13]. We also subjectively evaluated: inclusion and exclusion criteria; follow-up rates; participants lost to follow-up; comparator populations; and competing interests. We did not use quality assessments to exclude studies.

We plotted absolute scores against time and calculated a weighted mean based on the number of replies. For studies that repeated assessments, we calculated and plotted the change in score per month against the time midpoint for that period. We did not correct for multiple testing. Figures were plotted using R Core v3.4.1 [14]. Where studies reported a normal (reference) population for comparison with means and standard deviations, we compared these with the results for each domain for those discharged from an ICU using an unpaired Student's t-test. We considered SF-12 mental component summary and physical component summaries comparable to SF-36 [15]. We considered RAND-36 comparable to SF-36 in all domains except pain and general health [16]. We considered SF-20 the same as SF-36 except for vitality and emotional role domains. We categorised studies into one of three sub-groups, depending on the population: an unselected general cohort of patients discharged from an ICU; a selected cohort that stayed more than 5 days in an ICU [17]; or a selected cohort admitted to an ICU with a diagnosis of sepsis.

Results

We identified 11,927 records from which we included 48 studies (Fig. 1 and See Online Supporting Information, Table S1). Fifteen studies scored 6 or more on the Newcastle-Ottawa scale (see also Supporting Information, Appendix S1 and Table S3) [18–32]. Many of the other studies scored a maximum of 5 due to their cross-sectional design without comparator. Response rates exceeded 50% in 41 of 48 studies (See Online Supporting Information, Table S1). Response rates were greatest in studies that used an interview for few participants and lowest for studies that sent postal questionnaires to many participants. Assessments were most commonly performed 6 months and 12 months after ICU or hospital discharge.

Twenty-five studies investigated a general ICU patient cohort [20, 23, 25, 26, 28–30, 32–37, 39–49, 66]. Nineteen studies selected patients who required either level-3 care or prolonged ICU care [18, 19, 21, 24, 31, 50–63]. Five studies selected patients admitted to an ICU with sepsis [22, 27, 46, 64, 65]. One study reported a general patient cohort and those diagnosed with sepsis [46]. Thirty studies used the 'Short Form' family of surveys (SF-36, RAND-36, SF-20 and SF-12) [18, 19, 21–23, 25–28, 30, 33–37, 39–41, 50–56, 59, 62, 64–66]. Twenty studies used the EQ-5D; this was more commonly used after 2010 [18, 21, 24, 29, 32, 40–47, 54–58, 63, 64]. Two studies reported Self-Image Profile [31, 61] and one Nottingham Health Profile [60]. The Quality of Life

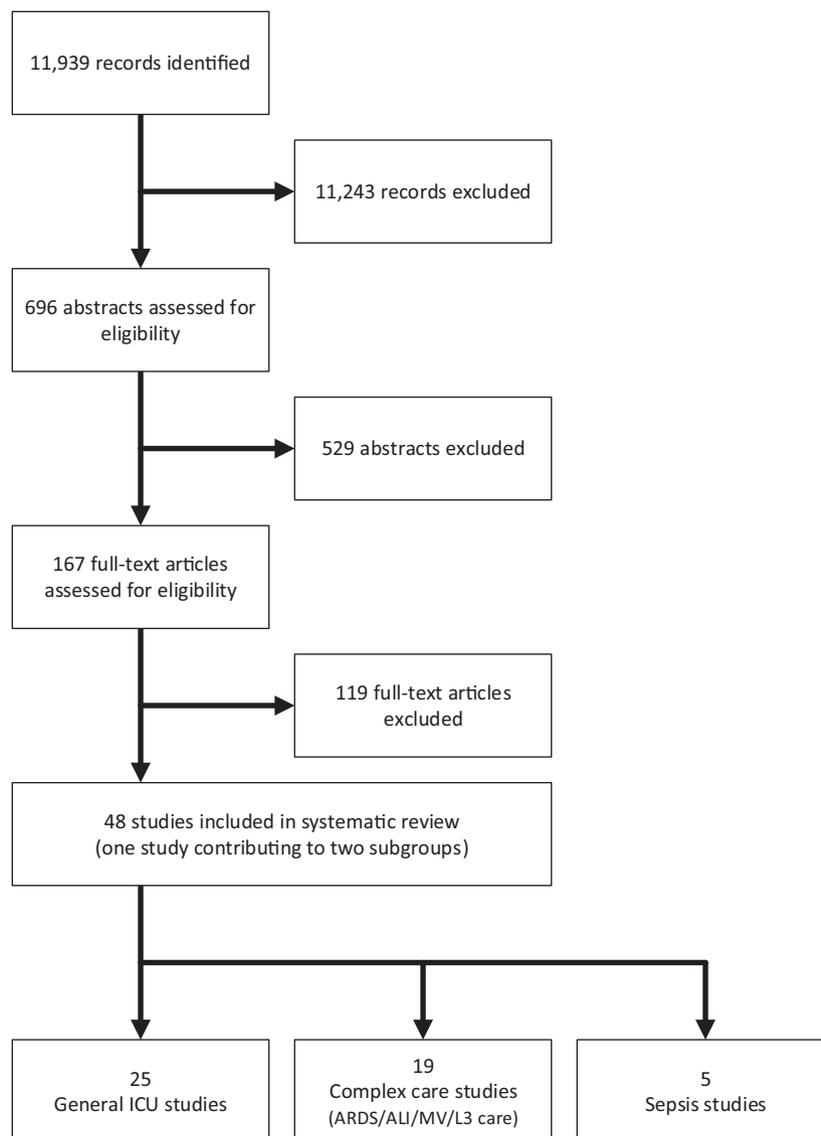


Figure 1 The search of the literature for studies of health-related quality of life after critical illness and the systematic selection of 48 studies for narrative review.

Spanish [20], RAND-36 [48] and SF-20 [49] tools were each used in one study. Seventeen studies compared their results to a reference population [18, 19, 22–24, 26, 27, 29, 34, 40, 41, 48–50, 60, 64, 66]. Twenty-five studies repeated assessments [18–23, 25, 31, 34, 35, 39, 41, 47–49, 51–54, 56–59, 64, 66]. Fifteen studies used the same measure to retrospectively determine quality of life before hospital admission [18–23, 25, 27, 28, 40, 52, 54, 58, 63, 65].

The estimated quality of life before admission to hospital was always worse than normal for a similar population, except for one study of septic patients. Quality of life remained worse than the reference population in most studies until follow-up was complete (see also Supporting Information, Table S2), except for the domains

of emotional role and mental health, which sometimes fully recovered six or more months after discharge.

Figure 2 summarises the weighted mean domain scores and their change up to 5 years after hospital discharge for populations of general ICU survivors in 14 studies that used the short form (SF) surveys [23, 25, 26, 30, 34–37, 39, 40, 46, 48, 49, 66]. Quality of life was always worse than population norms for all domains except bodily pain. We did not plot results for three studies: two reported median scores [28, 33], and the results in one study were inconsistent with their methods [67]. Mean physical function, physical role, vitality and social function always improved during the first 6 months after hospital discharge, whereas the summary of physical components and mental

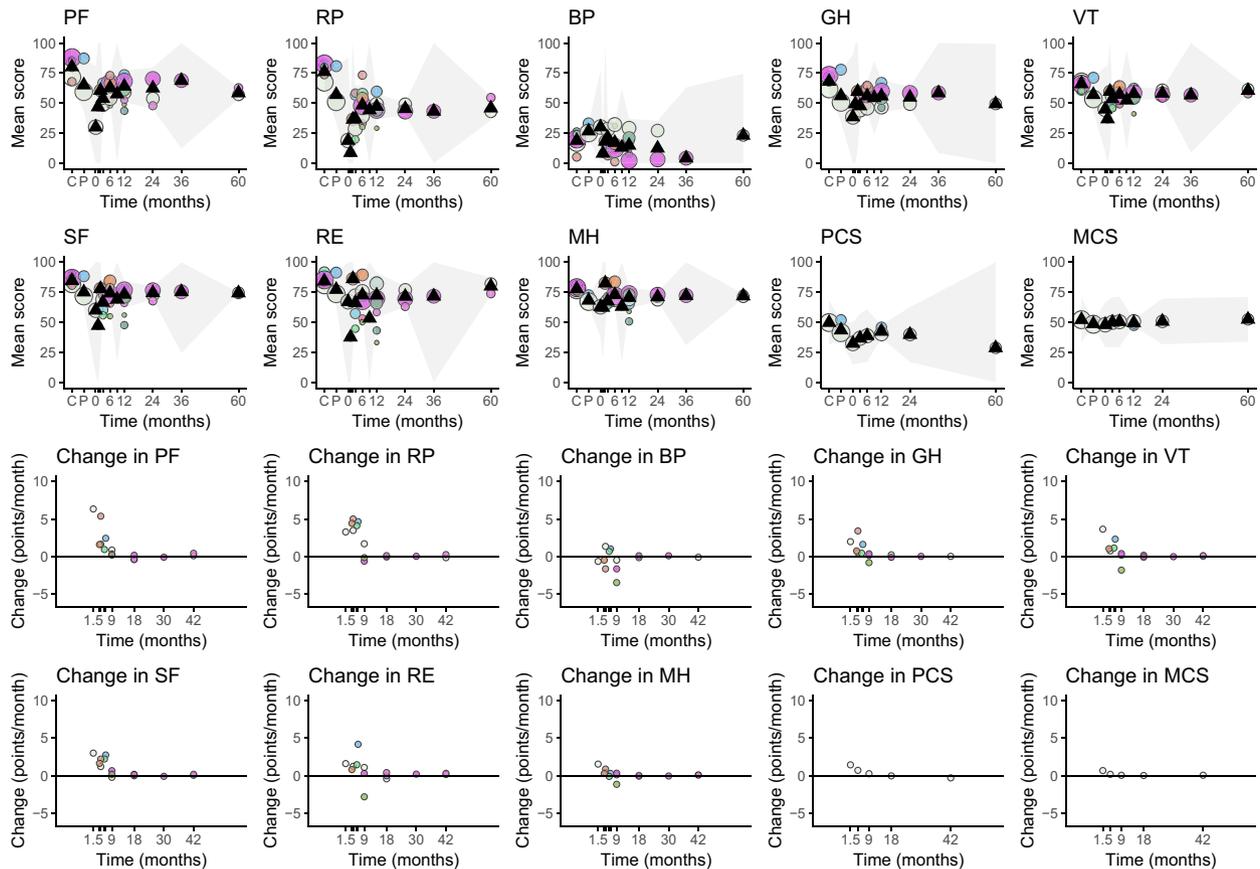


Figure 2 General ICU population – bubble plots of mean SF36v2 domain score against time (top two rows) and change in score against time (bottom two rows). Black triangles denote the weighted mean at each time-point, the grey overlay denotes the 95% CI of the weighted mean (where calculable). Each colour represents a different study with circle area proportional to the number of participants. Headers: PF, physical functioning; RP, physical role functioning; BP, bodily pain; GH, general health perceptions; VT, vitality; SF, social role functioning; RE, emotional role functioning; MH, mental health; PCS, physical component score; MCS, mental component score. C, control; P, before ICU.

components changed little. One study reported the Quality of Life in Spanish without reference to population norms, with findings similar to the SF surveys [20]. Figure 3 summarises the equivalent scores for 10 studies that used the EQ-5D-3L and EQ VAS up to 12 months after hospital discharge [29, 32, 40–47]. Two studies reported more than one time-point [41, 47], one of which reported improved scores with time.

Supplementary Information (Fig. S1) summarises the weighted mean domain scores and their change up to 5 years after hospital discharge for populations of patients requiring complex care in 12 studies that used the SF surveys [18, 19, 21, 50–56, 59, 61]. Quality of life was always worse than population norms, including before hospital admission. Mean physical function, physical role, vitality and social function generally improved in the first 5 months after discharge. Supplementary Information

(Fig. S2) summarises the equivalent scores for nine studies that used the EQ-5D up to 12 months after hospital discharge [18, 21, 24, 54–58, 63]. Population domain norms were not reported. Quality of life, in domains other than anxiety and depression, improved after discharge, except in two studies that reported EQ-5D-3L index scores [18, 56], neither of which reported changes with time. The EQ-5D-VAS was reported in three studies, one of which reported an improvement in quality of life with time [54]. Quality of life remained worse than population norms [18, 24, 63].

Supplementary Information (Fig. S3) summarises the weighted mean domain scores and their change between 6 months and 5 years after hospital discharge for populations of septic patients in four studies that used the SF surveys [22, 27, 64, 65]. Quality of life was always worse than population norms, except for Total Body Pain. Physical

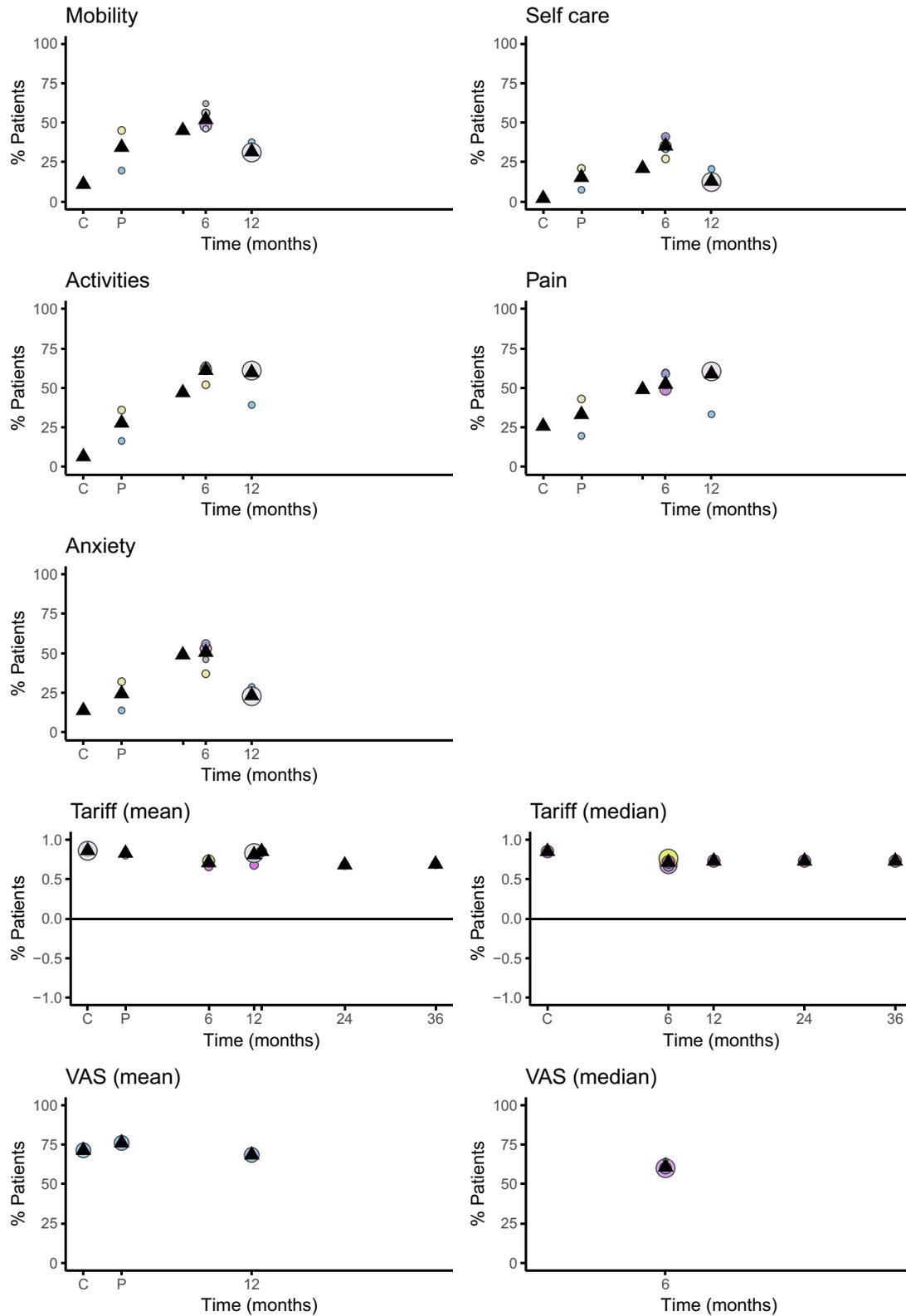


Figure 3 General ICU population – bubble plots of the percentage of participants reporting problems in answer to each EQ-5D domain and the corresponding mean or median EQ-5D tariff score and visual analogue scale against time. Black triangles denote the weighted mean at each time-point. Each colour represents a different study with circle area proportional to the number of participants. C, control; P, before ICU.

function, physical role and social function improved within 5 months of discharge. Quality of life did not improve 42–60 months after discharge [64]. Two studies used EQ-5D [46, 64]. One [18] reported multiple time-points and showed no improvement with time. No comparisons were made with population controls or pre-hospital assessment in EQ-5D domains.

Discussion

In this systematic review, patients surviving critical illness had worse health-related quality of life when compared with population norms. Quality of life incompletely recovered after hospital discharge. This was consistent for populations with heterogeneous critical illnesses, septic populations and populations ventilated for more than 5 days.

Some systematic reviews have suggested that health-related quality of life may return to population norms more than one year after discharge, whereas others have not [68–70]. Three papers that we did not include, two of which preceded 2000 and the other took a long time to recruit participants, have suggested that most survivors have a good quality of life 1–6 years after hospital discharge [71–73]. It has also been suggested that septic populations and those with prolonged critical care have worse quality of life than other patients discharged from critical care [9]. Our paper does not support either contention. Our study suggests that the greatest health improvements occur in the first year after discharge from hospital, with little further improvement for all sub-groups and in all health domains. This suggests that interventions to improve health after critical illness might be most effective in the first year after hospital discharge.

Health-related quality of life scores for populations, had they not been critically ill, are usually estimated from population norms, provided by copyright holders for the EuroQoL or Short Forms, or from survivors trying to remember their health before they became critically unwell. The weakness of using population norms is that they do not account for pre-existing morbidity. The accuracy of recalled health is uncertain, although it might be reasonable up to 3 months after hospital discharge [74]. In our review, health before critical illness recalled by patients was worse than population norms. This suggests that much of the 'failure to recover' (to population norms) indicates recovery to pre-existing chronic illness by patients who overestimated their previous quality of life. However, critical illness is likely to permanently worsen the health of patients with chronic disease [41]. The most appropriate comparison group

varies with the purpose of the comparison. The development of interventions to improve health-related quality of life would be informed by the net change in the health of large cohorts of patients who have survived critical illness. Healthcare economics would be better informed by gross changes in health. Population norms are most useful in identifying the domains of health that are most affected by critical illness.

There is increasing emphasis on the psychological sequelae of admission to intensive care [38, 75–78]. In general, critical illness affects psychological health less than physical health and therefore can improve less after hospital discharge. Interventions to improve health after critical illness might be more successful for physical health than psychological health and sample size calculations for clinical trials should incorporate smaller effect sizes for psychological interventions.

Two factors that might limit the applicability of our findings are the high mortality from critical illness and the loss of many patients during follow-up. We think that the high mortality rate – relative to the general population – does not inherently bias our results, providing that mortality is accurately and independently tracked. Health probably affects patient participation during months and years of follow-up: the health of participants under surveillance might be better than the health of participants lost to surveillance. Only half of the studies in our review compared health with a reference population, whereas comparison with a large cohort who had survived critical illness was not used by any study, which we think would be the most helpful comparison. We felt that the variety of tools used to measure health-related quality of life precluded quantitative pooling of results.

Future research should report SF-36 as one measure of health-related quality of life after critical illness, as it would allow comparison with most published studies, repeated within the first year to capture most of the change in quality of life that might be affected by interventions. Methods should be developed to better establish quality of life before critical illness and to adjust for pre-existing disease.

In conclusion, health-related quality of life after critical illness was most often measured with SF-36. Quality of life after critical illness was worse than age- and sex-matched norms. Improvements in quality of life occurred in the first year after discharge in four domains: physical function; physical role; vitality and social function. Interventions to aid recovery after critical illness are most likely to have an effect in the first year after hospital discharge.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Figure S1. Bubble plots of mean domain score against time and change (expressed in points per month) against time.

Figure S2. Bubble plots of the percentage of people reporting problems in answer to each EQ-5D domain and the corresponding mean or median EQ-5D tariff score and visual analogue scale against time.

Figure S3. Bubble plots of mean domain score against time and change (expressed in points per month) against time.

Table S1. Papers investigating a health-related quality of life after critical illness, arranged by: population studied; assessment tool and then alphabetically.

Table S2. Time points with scores significantly different from population comparisons.

Table S3. Newcastle–Ottawa Score for cohort studies.

Appendix S1. Newcastle–Ottawa quality assessment scale for cohort studies.

Appendix S2. PubMed search.