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Intensive care diaries to promote recovery for patients and families after critical illness: a Cochrane Systematic Review

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## **Intensive Care diaries to promote recovery for patients and families after critical illness: a Cochrane Systematic Review**

### **Abstract:**

**Objectives:** To assess the effect of an intensive care unit (ICU) diary versus no ICU diary on patients, and their caregivers or families, during the patient's recovery from admission to an ICU.

**Design:** Systematic review of randomised controlled trials (RCTs) and clinical controlled trials.

**Data sources:** CENTRAL, MEDLINE, CINAHL, EMBASE, PsycINFO, PILOT; Web of Science Conference Proceedings, clinical trial registries and reference lists of identified trials.

**Review methods:** Studies evaluated the effectiveness of patient diaries, when compared to no ICU diary, for patients or family members to promote recovery after admission to ICU were included. Outcome measures for describing recovery from ICU included the risk of post-traumatic stress disorder (PTSD), anxiety, depression and post-traumatic stress symptomatology, health-related quality of life and costs. We used standard methodological approaches as expected by The Cochrane Collaboration. Two review authors independently reviewed titles for inclusion, extracted data and undertook risk of bias according to pre-specified criteria.

**Results:** We identified three eligible studies; two describing ICU patients (N = 358), and one describing relatives of ICU patients (N = 30). No study adequately reported on risk of PTSD as described using a clinical interview, family or caregiver anxiety or depression, health-related quality of life or costs. Within a single study there was no clear evidence of a difference in risk for developing anxiety (RR 0.29, 95% CI 0.07 to 1.19) or depression (RR 0.38, 95% CI 0.12 to 1.19) in participants who received ICU diaries, in comparison to those that did not receive a patient diary. Within a single study there was no evidence of difference in median post-traumatic stress symptomatology scores (diaries 24, SD 11.6; no diary 24, SD 11.6) and delusional ICU memory recall (RR 1.04, 95% CI 0.84 to 1.28) between the patients recovering from ICU admission who received patient diaries, and those who did not. One study reported reduced post-traumatic stress symptomatology in family members of patients recovering from admission to ICU who received patient diaries (median 19; range 14 to 28), in comparison to no diary (median 28; range 14 to 38).

**Conclusions:** Currently there is minimal evidence from RCTs of the benefits or harms of patient diaries for patients and their caregivers or family members. A small study has described their potential to reduce post-traumatic stress symptomatology in family members. However, there is currently inadequate evidence to support their effectiveness in improving psychological recovery after critical illness for patients and their family members.

*This article is based on a Cochrane Review published in the Cochrane Database of Systematic Reviews (CDSR) 2014, Issue 12, DOI: 10.1002/14651858.CD10468 (see [www.thecochranelibrary.com](http://www.thecochranelibrary.com) for information). Cochrane Reviews are regularly updated as new evidence emerges and in response to feedback, and the CDSR should be consulted for the most recent version of the review*

**Keywords:**

Anxiety; Depression; Intensive Care; Post traumatic stress; Recovery

## Introduction

### *Recovery from critical illness*

Critical illness requiring admission to an intensive care unit (ICU) continues to increase in frequency around the world. As advances in health care are realized, more patients are surviving their stay in ICU but the implication of this is that there is an increase in the number of patients experiencing challenges during the recovery phase. During their ICU admission, patients experience extreme physical and psychological stressors including critical illness, delirium, fear, lack of privacy, noise, pain, sedation administration, sleep deprivation, and the abnormal ICU environment [1-3]. These experiences impact on a patient's recovery from critical illness, which can be a complex and protracted process [4]. Within this recovery period, patients may experience both physical (e.g. neuropathy, reduced mobility, and breathlessness) and psychological disorders (e.g. depression and post-traumatic stress) [5].

Psychological disorders, as well as anxiety and depressive symptomatology, are commonly reported in patients and their caregivers after ICU admission. However, not every patient in ICU will develop psychological symptoms or a disorder; many individuals will be resistant or resilient to the effects of the ICU. Many who show distress will return quickly to normal function and some with a psychological disorder will follow a recovery trajectory [6]. Cross-sectional and cohort studies have reported anxiety and depression conditions in patients recovering from ICU admission at a higher rate than the general population, at between 24% and 45% at six weeks [7], three months [8] and one year [9] after ICU admission. Anxiety and depression conditions often co-exist with post-traumatic stress disorder (PTSD) [10]. PTSD is a serious disorder that follows the experience of a traumatic event and causes significant impairment in daily life [11]. The experience of the stressor generates feelings of intense fear, horror, helplessness, threat to life and physical integrity for the individual or someone to whom they have close affectional ties [11].

In addition to anxiety, depression and PTSD, ICU survivors have often reported the absence of factual memory and the occurrence of delusional memories, including hallucinations or nightmares, throughout their recovery period [7]. ICU-related delusional memories are estimated to be present in around 30% to 70% of patients [10, 12, 13], are often persecutory in nature, and tend to be recalled with high vividness and in substantial detail [2]. The direct cause of these delusional memories is unknown but is thought to be related to a combination of medication (including adrenaline, corticosteroids, opiates and sedative drugs such as propofol and benzodiazepine), sleep deprivation, and critical illness [12]. The literature surrounding the relationship between recall of absent, traumatic or delusional memories and psychological disorders is mixed, with different authors finding positive [10, 12, 14, 15] and negative associations [7, 16]. The association between delusional memories and the psychological distress of ICU survivors has been mainly attributed to the strong vividness with long duration and high emotional content of these memories when compared with memories of real events [13].

Research is now focusing on improving the long-term holistic health outcomes of ICU survivors. Psychological distress, including anxiety, depression and PTSD symptomatology, compromises the recovery of ICU survivors and has been increasingly identified as a serious problem. The challenge lies with clinicians and researchers to develop strategies to effectively manage and treat this

psychological distress alongside and following life-saving physical treatment to maximize a patient's recovery.

### *Intensive Care Unit (ICU) diaries*

One strategy that has been developed and implemented by clinical staff to treat the psychological distress prevalent in ICU survivors is patient diaries. Patient diaries provide a record of events which occur throughout a patient's admission to the ICU. Following a timeline design, they provide a background to the cause of the patient's ICU admission and an ongoing narrative outlining day-to-day activities [17]. Diversity of practice exists throughout ICUs in implementing patient diaries, including variation in structural, content and process elements.

Emerging in Scandinavia in the 1970s to 1980s [18], multiple authors have outlined the introduction and evaluation of patient diaries both within their local ICUs and internationally. Patient diaries are generally written prospectively and addressed personally to the individual patient. ICU staff provide an overall structure for the diary, with a cover and sometimes a preprinted introduction and glossary of terms and equipment [19-21]. Diaries are generally structured with a summary outlining the reason and event of admission to ICU, daily entries, and a final note on discharge or transfer from the ICU [21].

Primary authorship is predominantly the responsibility of the bedside ICU nurse. Some ICUs encourage the participation of the patient's family, reporting the diaries as a potential focus for family empowerment and family-centred care [22, 23]. Current practice surrounding the provision of patient diaries to the patients is variable. ICUs differ between putting the diaries on the end of the bed when transferring a patient out of ICU to delivering a coordinated system of follow-up and support for the patients and their families [20, 21, 23].

### *ICU diaries to improve recovery from critical illness*

Personal diaries are used by individuals to reflect on significant aspects of their lives and serve as a vehicle for construction, reconstruction and narration of stories [24]. Patient diaries differ from personal diaries in that they are not first-person accounts. Nurses, hospital staff, family or friends vicariously write for the patient while the patient is unable to write due to altered state of consciousness, weakness or physical impairment [24].

Patients' perceptions of intensive care are variable, often with very little or indeed nothing at all being remembered [14]. For many patients their memories are unpleasant, fragmentary or frightening in nature [23]. The aim of patient diaries is to provide ICU survivors with an accurate and informative collection of events, improving the memory recall of factual information. Delusional memories have been associated with anxiety, depression, post-traumatic stress symptomatology [9, 12] and poor health-related quality of life [16]. The aim of a diary is to provide a coherent narrative of the illness period, clarifying gaps in memory and diminishing the impact or dominance of imagined occurrences and hallucinations [18]. It has also been suggested that diaries can be used by relatives to encourage the healing process, after their own vicarious traumatic experience or as a basis for discussion about the patient's illness experience [10].

In comparison to this therapeutic view on patient diaries, there is, however, considerable concern regarding the method of providing this information and their use to reflect and reconstruct

memories, thereby acting as a debriefing tool. Debriefing is a psychological treatment intended to reduce the psychological morbidity that arises after exposure to trauma [25]. It involves promoting some form of emotional process, catharsis or ventilation by encouraging recollection, ventilation or reworking of the traumatic event [25]. Since the 1990s debriefing has come under intense scrutiny, and a Cochrane review in 2002 [25] found no evidence that single session individual psychological debriefing interventions prevented the onset of PTSD or reduced psychological distress. In addition to the lack of evidence, the majority of criticism was levelled at the timing of the debriefing, suggesting that during the immediate period after stress there is a substantial risk of causing retraumatization and inhibiting the individuals' ability to normally process the traumatic event [26]. Providing sensitive and private information without a supportive process could potentially cause significant psychological harm, negatively impacting a patient's recovery.

The provision of psychological support to improve recovery after critical illness requires a complex intervention. As described by the Medical Research Council [27] complex interventions comprise of a number of separate elements which seem to be essential to the proper functioning of the intervention, although the 'active ingredient' can be difficult to specify. Separating the content in patient diaries from the method of providing them (e.g. the clinician's skill, conversation, return to ICU) and other active elements of psychological support is difficult.

### *Significance*

Annual estimates suggest that more than 20 million patients require treatment in ICUs worldwide in order to manage critical illnesses, injuries or exacerbations of chronic conditions[28]. The combined after-effects of critical illness and the ICU experience have been linked to short and long-term psychological compromise, which can significantly impair psychological and physical patient recovery [1, 2]. This results in a significant emotional, physical and financial burden to patients, families and society. Clinicians have developed and used patient diaries as a tool to treat psychological distress. However, it has not been established whether this is an effective practice or whether it may have an adverse psychological impact due to individual patient factors, author emphasis, or the method of feedback support or lack thereof.

### **Objectives**

To assess the effect of a diary versus no diary on patients, and their caregivers or families, during the patient's recovery from admission to an ICU.

### **Methods**

The Cochrane systematic review protocol was registered and published prior to review commencement[29].

### *Eligibility criteria*

We included all randomized controlled trials (RCTs) and controlled clinical trials (CCTs) that evaluated the effectiveness of patient diaries for their impact on recovery after admission to ICU. CCTs refer to quasi-randomized studies where, although the trial involves testing an intervention and control, concurrent enrolment and follow-up of intervention and control-treated groups, the method of allocation is not considered strictly random [30]. We included studies irrespective of



publication status, year of publication or language. We excluded non-randomized studies such as cohort studies because of the increased potential for bias. We also excluded cross-over trials as this methodology is not suitable for evaluating an intervention that must be given at a specific time point.

We included all patients who were admitted to an ICU and their family members or caregivers. We included patients irrespective of age, country and critical illness severity. The primary intervention under investigation was patient diaries provided by ICU staff. We included any RCT or CCT in which the presence or absence of patient diaries was the only difference between treatment groups. For the purpose of this review, patient diaries were defined as a prospectively written collection of events which occurred during the ICU stay, authored by staff or relatives, or both [1, 31]. Primary and secondary outcomes are described in table 1.

<Insert Table 1>

### *Identification of studies*

We searched the Cochrane Central Register of Controlled Trials (CENTRAL2014, Issue 1), Ovid MEDLINE (1950 to January 2014), Ovid EMBASE (1980 to January 2014), PsycINFO (1950 to January 2014), Published International Literature on Traumatic Stress (PILOTS) database (1971 to January 2014); EBSCOhost CINAHL (1982 to January 2014) and Web of Science Conference Proceedings Citation Index - Science and Social Science and Humanities (1990 to January 2014). A detailed search strategy for CENTRAL is provided in Table 2. There were no restrictions on the basis of date, language or publication status. We also searched the following clinical trial registers:

- Australian and New Zealand Clinical Trials Register ([www.anzctr.org.au](http://www.anzctr.org.au));
- Clinical Trials.gov ([www.clinicaltrial.gov](http://www.clinicaltrial.gov));
- Current Controlled Trials ([www.controlled-trials.com/mrct](http://www.controlled-trials.com/mrct));
- Hong Kong Clinical Trial Register ([www.hkclinicaltrials.com](http://www.hkclinicaltrials.com));
- Clinical Trials Registry - India ([www.ctri.in](http://www.ctri.in));
- UK Clinical Trials Gateway ([www.controlled-trials.com/ukctr/](http://www.controlled-trials.com/ukctr/)); and
- World Health Organization (WHO) Clinical Trials Registry Portal ([www.who.int/trialsearch](http://www.who.int/trialsearch)).

<Insert Table 2>

We hand searched bibliographies of all retrieved and relevant publications identified by these strategies for further studies. We contacted experts in the field to ask for information relevant to this review.

### *Study screening*

We combined the results of the searches and excluded duplicate records. Two review authors (AU and LA) independently assessed titles and abstracts of retrieved studies for relevance. After initial assessment we retrieved full versions of all potentially eligible studies. The same two review authors then independently checked the full papers for eligibility. We resolved discrepancies between review authors through mutual discussion and, where required, consulted a third independent review author (RB).

### *Data extraction*

We extracted the details from eligible studies and summarized them using a data extraction sheet. The data extraction sheet was developed in conjunction with the Cochrane Anaesthesia Review Group (CARG). Two review authors (AU and LA) extracted data independently and then cross-checked for accuracy and agreement. Where necessary, we resolved any discrepancies through discussion and arbitration with a third review author (RB). We included studies that had been published in duplicate once only. When data were missing from the papers, we contacted study authors to retrieve the missing information.

#### *Assessment of risk of bias in included studies*

Two authors (AU and LA) independently assessed each eligible study for quality and bias using the 'Risk of bias' assessment tool described in Chapter 8 of the *Cochrane Handbook for Systematic Reviews of Interventions* [32]. We resolved disagreements by discussion and when we could not reach a consensus a third author (RB) arbitrated. The bias tool addresses six specific domains, namely sequence generation, allocation and concealment, blinding, incomplete outcome data, selective outcome reporting, and other issues which may potentially bias the study [32]. We reported the 'Risk of bias' table for each eligible study and outcome using the categories of low, high or unclear risk of bias.

We intended to conduct sensitivity analyses to determine whether excluding studies at high risk of bias would affect the results of the meta-analysis. However, due to the small number of studies, we have not performed a meta-analysis.

#### *Data analysis*

We generated measures of treatment effect for each of the reported categorical dichotomous outcomes, providing risk ratios (RR) and 95% confidence intervals (CI). A meta-analysis was not conducted due to the small number of studies eligible for inclusion in the review. There were no unit of analysis issues as the patient and caregivers were the unit of analysis for all included studies. We planned to consider clinical, methodological and statistical heterogeneity. Due to the small number of included studies, we have not undertaken a meta-analysis, so assessment of statistical heterogeneity has not been performed. Clinical and methodological heterogeneity of the included studies are discussed within the conclusions section of this review.

#### *Missing data*

Authors of included studies were emailed to ask for further information and clarification of key aspects of their study methods. All contact authors responded [33-35], with one author group able to provide all information required [34].

## **Results**

### *Search results*

The results of the search and selection of studies are summarized in the PRISMA study flow diagram Figure 1[36]. The search of electronic bibliographic databases identified 1485 records, of which 46 were duplicate records. Searches of clinical trial registries did not identify additional studies, but the

hand searching of bibliographies identified one study for potential inclusion. Of the 1439 titles screened, 1427 were excluded. Twelve full text articles were screened for potential inclusion, of which nine were excluded due to study design [1, 22, 37-43]. This was because they did not use an RCT or CCT design. These included observational studies [22, 38, 40-43], a prospective cohort study with retrospective reference group [39], time-series design [1] and a commentary paper[37].

< Insert Figure 1 >

#### *Included studies*

Three studies were eligible to be included in the review. The characteristics of the three eligible studies are described in Table 2. Jones and colleagues undertook a RCT involving patients and family members, and reported their results in two separate publications [33, 34].

<Insert Table 3>

The Jones, Backman [34] study was conducted in six European countries (Sweden, Italy, Denmark, Norway, Portugal, United Kingdom) with two ICU sites per country. Participants (N = 322) were admitted to ICU for at least 72 hours and ventilated for at least 24 hours. Knowles and Tarrier [35] studied 36 adult participants recovering from admission to a single British ICU. Participants were admitted to ICU for at least 48 hours and were not necessarily ventilated. Both studies excluded participants who had pre-existing psychotic illnesses. Backman and Walther [38] also excluded patients who had a diagnosis of dementia or an organic memory problem. Jones, Backman [34] excluded patients who were too confused to give informed consent. From the original study by [34] Jones, Backman [34] a substudy of family members was undertaken and reported in Jones, Backman [33]. They studied 30 family members of the previous study participants from ICUs in the United Kingdom and Sweden. No specific exclusion criteria were reported.

All studies [33-35] compared the use of patient diaries to no diaries, with participants randomly assigned to one or the other. All studies described the patient diary as being a daily record of the patient's ICU stay and the study protocol dictated a standardization of the patient diary content via the use of either a template[33, 34] or topic headings (e.g. patient's appearance and condition, events on the ward)[35]. Jones, Backman [34] and Jones, Backman [33] included photographs of the participant during their ICU in the patient diary; Knowles and Tarrier [35] did not. Diaries were authored by a multidisciplinary group of ICU staff with [33, 34] or without [35] family member involvement. In the Knowles and Tarrier [35] study, the diary was handed over by a specifically trained ICU nurse consultant, who read it with the patient and answered any questions arising in a verbal feedback session. In the Jones, Backman [34] and Jones, Backman [33] studies the diary was introduced, either face-to-face or over the phone, by a research nurse or a medical doctor who ensured that the participants understood its contents.

#### *Methodological quality of studies*

Jones, Backman [34] and, by extension, Jones, Backman [33] reported a detailed computerized block randomization process and effective measures for allocation concealment. Knowles and Tarrier [35] reported unclear information regarding their sequence generation and allocation concealment

within their publication. However, when privately emailed, they reported the use of adequate allocation concealment involving opaque sealed envelopes.

Due to the unblinded nature of the intervention, performance bias was inevitable, but it was possible for some outcomes to be assessed without knowledge of the participants' allocation. Knowles and Tarrier [35] reported that the principal investigator who undertook the outcome assessment was not blinded, introducing the possibility of bias. The outcomes from Jones, Backman [34] and Jones, Backman [33] included in the review were by self-report tools and, due to the nature of the intervention, the participants were aware of their study group. It was not clear whether the researchers collating the questionnaire results were blinded to study group.

All studies reported minimal losses after randomization, demonstrating minimal attrition bias. Jones, Backman [34] and Jones, Backman [33] registered the clinical trial, Knowles and Tarrier [35] did not register their trial and stated they did not report all outcomes. We found no other potential sources of bias in Jones, Backman [34] and Jones, Backman [33]. In Knowles and Tarrier [35] there were significant differences between control and experimental groups including ICU length of stay and severity of critical illness, both of which are associated with increased risk of PTSD.

#### *Effectiveness of interventions*

Due to the small number of studies eligible for inclusion in our review and the diverse outcomes reported, we were not able to undertake a meta-analysis. A table summarizing the outcomes from the single studies across the available outcomes has been provided in Table 3.

*<Insert Table 4>*

## **Discussion**

No studies reported our first primary outcome measure describing the risk of PTSD in patients recovering from admission to ICU using a structured clinical interview. We applied this definition a priori as it is supported by the American Psychiatric Association [11] as the gold standard for the diagnosis of PTSD. Jones, Backman [34], when attempting to reduce the risk of detection bias in the diagnosis of PTSD, trained the interviewers in the administration, but not the meaning or scoring, of the items in the instrument. The use of an uninformed clinician makes the interview no longer diagnostic, and limits its reliability as an assessment tool. Therefore, we did not include these results in the Cochrane Review. There is currently no general agreement on which outcomes should be measured in trials focusing on psychological recovery after critical illness. Such agreement would be beneficial to aid consistency across relevant trials [44].

A single study [35] reported the potential effectiveness of patient diaries to reduce the risk of anxiety and depression in comparison to no patient diary. However, these results were not statistically significant and the study was methodologically limited due to poor sample size. Knowles and Tarrier [35] reported the cut-off score of "clinically significant anxiety and depression" of eight. While "caseness" of anxiety and depression is best described by a score range of 11 or higher [45, 46], the score of eight or greater is "just suggestive of the presence of the respective state".

There was no evidence of an effect on post-traumatic stress symptomatology between patients who did or did not receive patient diaries three months after ICU admission, although there was a significant decrease in post-traumatic stress symptomatology in the intervention arm for family members. The reliability of these results is limited as the chosen instrument for measuring post-traumatic symptomatology used in these studies (PTSS-14) has not been adequately validated in the revised form after four new items were added to the original PTSS-10. While the PTSS-14 has been correlated with a better measure in a small study (N = 44), it was designed as an early screening tool that incomprehensively lists post-traumatic stress symptoms, but does not link the symptoms to a trauma or event [47].

There is evidence to suggest that patients' psychological health after the ICU continues to be problematic beyond three months, suggesting that the follow-up timeline in each of these included studies was insufficient [48-50]. For the study undertaken by Knowles and Tarrier [35], the reduction of anxiety and depression was measured only three weeks after receiving the patient diary intervention. Further studies are needed to assess the long-term impact of patient diaries on depression, anxiety and post-traumatic stress.

The recall of delusional memories was comparable between study groups. Researchers [19] have previously discussed the role of the patient diary in the provision of a coherent narrative of the illness period, diminishing the impact or dominance of imagined occurrences and hallucination.

The studies included in this systematic review addressed some important outcomes related to the effectiveness of patient diaries to support recovery from critical illness. However, other outcomes including risk of PTSD in patients recovering from admission to ICU, anxiety or depression in caregivers or family members of patients recovering from admission to ICU, caregiver or family member satisfaction, health-related quality of life in patients recovering from admission to ICU or costs of daily implementation were not reported. The single study outlining the risk of anxiety and depression for patients recovering from admission to ICU had only 36 participants. More research is needed to inform these outcomes. In addition, all studies included in this review were undertaken in adult ICUs within Europe and the UK. Generalizability of the results is limited to these populations and geographical areas.

None of the included studies adequately described the multi-dimensionality of the patient diary intervention, in terms of its characteristics as a complex intervention. The manner and time in which the patient diary was provided, the skills and qualification of the clinician providing the patient diary and the co-interventions that these entail have not been adequately explored. These elements may have an important contribution to the effectiveness of a patient diary to improve, or worsen, patient and family member recovery.

The studies included within this review were carried out in European countries including Sweden, Italy, Denmark, Norway, Portugal and the United Kingdom. This is in accordance with the majority of reported patient diary usage which has been within Europe, particularly Scandinavia [18-20, 51] and the United Kingdom [22, 52].

The quality of the evidence contained in the review has been assessed using the GRADE approach [53]. While publication bias, indirectness and inconsistency were not established, the methodologic

quality and precision of the effect estimates was low to very low. This has meant that the overall confidence with the quality of evidence contained in the review is low.

Clearly described procedures were followed to prevent potential bias in the review process. A careful literature search was conducted and the methods used are transparent and reproducible. None of the review authors has reported any conflict of interest.

Observational [22, 38, 40-43], prospective cohort with a retrospective reference group [39], time-series[1] and qualitative [52, 54-57] studies have reported the success and importance of patient diaries in the clinical setting. Our review has demonstrated the paucity of randomized controlled trials evaluating patient diaries.

## **Conclusions**

### *Implications for practice and research*

Currently minimal evidence from RCTs is available to evaluate the effectiveness of patient diaries to promote recovery from critical illness for patients and caregivers or family members. Studies limited by small sample sizes have examined the potential of diaries to reduce post-traumatic stress symptomatology in family members. However, there is currently inadequate evidence to support their effectiveness in improving psychological recovery after critical illness for patients and their family members. Fundamental concerns regarding the safety and effectiveness, specifically the method in which patient diaries are provided, needs to be considered. It has not been established whether patient diaries are an effective practice or whether it may have an adverse psychological impact.

Further research needs to be undertaken to ascertain the effect of patient diaries for patients and caregivers or family members recovering from ICU. Use of patient diaries for patients recovering from ICU admission is becoming more common, but it is not clear whether it is a safe and effective practice, therefore, further research is required.

When designing future research into the effectiveness of patient diaries, researchers should also carefully consider the complexity of the patient diary as an intervention, and consider the active components that may impact the diaries effectiveness. The entire intervention surrounding the development and provision of patient diaries, including content, process, timeline and personnel involved, needs to be adequately described within the research to enable future replication and generalizability. Multi-dimensional aspects of psychological recovery including anxiety, depression and symptoms of PTSD should be assessed for at least six and preferably twelve months after discharge from ICU[14]. Researchers should continue to plan their protocols to minimize risk of bias and should report clearly in accordance with the CONSORT guidelines [58]. Researchers should also carefully consider their choice of outcome measures, to ensure the validity of their research.

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**Table 1: Primary and secondary outcomes for systematic review**

<b>Primary outcomes</b>
1. Risk of post-traumatic stress disorder (PTSD) in patients recovering from admission to the intensive care unit (ICU), as assessed using a structured clinical interview [11]
2. Risk of anxiety in patients recovering from admission to ICU, as assessed using a tool with established reliability and validity such as the Hospital Anxiety and Depression Scale (HADS) [46]
3. Risk of depression in patients recovering from admission to ICU, as assessed using a tool with established reliability and validity such as the HADS [46]
<b>Secondary outcomes</b>
1. Risk of memory recall of ICU in patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
2. Post-traumatic stress symptomatology in patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
3. Post-traumatic stress symptomatology in caregivers or family members of patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
4. Risk of anxiety in caregivers or family members of patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
5. Risk of depression in caregivers or family members of patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
6. Carer or family member satisfaction, as described by the study investigator.
7. Health-related quality of life in patients recovering from admission to ICU, as assessed using a tool with established reliability and validity.
8. Costs, as described by the study investigator; including implementation and healthcare utilization costs.

**Table 2 CENTRAL search strategy**

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#1 MeSH descriptor: [Patients] explode all trees  
#2 MeSH descriptor: [Caregivers] explode all trees  
#3 MeSH descriptor: [Narration] explode all trees  
#4 (#1 or #2) and #3  
#5 ((patient\* or caregiver\*) and (diaries or diary or (narrat\* and (coherent or outlining))))  
#6 #4 or #5  
#7 MeSH descriptor: [Intensive Care Units] explode all trees  
#8 MeSH descriptor: [Critical Care] explode all trees  
#9 MeSH descriptor: [Critical Illness] explode all trees  
#10 ((critical\* near ill\*) or ((intensive care unit\* or ICU) and (recover\* or delusional memor\* or psychological distress or anxiety or depression or PTSD or bedside nurs\* or family or caregiver\* or recuperate\*)))  
#11 #7 or #8 or #9 or #10  
#12 #6 and #11

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ICU = Intensive care unit; MeSH= Medical subject heading; PTSD=Post traumatic stress disorder

**Table 3: Key characteristics of included studies**

<b>Jones, Backman [34]</b>	
<b>Methods</b>	Pragmatic, randomized controlled trial in six European countries, with two intensive care units (ICUs) per country.
<b>Participants</b>	352 adult ICU patients randomized, 322 completed study. Inclusion criteria: Admitted to ICU for > 72 hours; ventilated for > 24 hours. Exclusion criteria: Too confused to give informed consent; pre-existing psychotic illness (e.g. schizophrenia); diagnosed post-traumatic stress disorder (PTSD).
<b>Interventions</b>	ICU diary: a daily record of the patient's ICU stay, written in everyday language and accompanied by photographs. Authored by multidisciplinary healthcare staff and family. Diaries standardized via the provision of guidelines to each centre. The diary was introduced to the patient by a research nurse or doctor who ensured that they understood its contents but did not give any advice on what to do with it. This was done either face-to-face or over the phone. Controls: Received standard care at each setting. At several of the study sites, this involved giving patients verbal information about their illness prior to discharge from hospital. All control participants received the ICU diary after the final outcome assessment.
<b>Outcomes</b>	Patient ICU memory recall: assessed using the ICU memory test (ICUMT) at randomization (1-month post ICU discharge) and 3-month follow-up. Patient post-traumatic stress symptomatology: assessed using post-traumatic stress-14 at randomization and 3-month follow-up. Patient PTSD: assessed using post-traumatic diagnostic scale with a blinded clinician within a 'diagnostic' interview at the 3-month follow-up. Not included within this systematic review.
<b>Jones, Backman [33]</b>	
<b>Methods</b>	Pragmatic, randomized controlled trial in two European ICUs.
<b>Participants</b>	36 family members of adult ICU patients randomized; 30 completed the study. Inclusion criteria: Family members of those recruited to Jones, Backman [34]. That is, patients who were admitted to ICU for > 72 hours; ventilated for > 24 hours. Exclusion criteria: Too confused to give informed consent; pre-existing psychotic illness (e.g. schizophrenia); diagnosed post-traumatic stress disorder.
<b>Interventions</b>	ICU diary: a daily record of the family members' experiences of patients' ICU stay, written in everyday language and accompanied by photographs. Authored by multidisciplinary healthcare staff and family. Diaries standardized via the provision of guidelines to each centre. The diary was introduced to the family member by a research nurse or doctor who ensured that they understood its contents but did not give any advice on what to do with it. This was done either face-to-face or over the phone. Controls: Received standard care at each setting. At several of the study sites, this involved giving family members verbal information. All control participants received the ICU diary after the final outcome assessment.
<b>Outcomes</b>	Family member post-traumatic stress symptomatology: assessed using post-traumatic stress-14 at randomization and 3-month follow-up.
<b>Knowles and Tarrier [35]</b>	
<b>Methods</b>	Pragmatic, randomized controlled trial in a single British ICU.
<b>Participants</b>	36 adult ICU patients. Inclusion criteria: Admitted to ICU for > 48 hours.

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	Exclusion criteria: Age < 18 years or > 85 years; admitted following a deliberate suicide attempt; currently experiencing clinically significant psychological symptomatology which predated their admission to ICU; history of dementia or other organic memory problems.
<b>Interventions</b>	ICU diary: a daily record of the patient's ICU stay, authored by multidisciplinary healthcare staff. Diaries standardized under the headings: patient's appearance and condition, events on the ward, details of any treatment or procedures administered in lay language and the names of any visitors. The diary was handed over by the ICU nurse consultant who read it with the patient and answered questions in a verbal feedback session. Controls: Received standard care. All control participants received the ICU diary after the final outcome assessment.
<b>Outcomes</b>	Anxiety: assessed using Hospital Anxiety and Depression Scale; at initial assessment (1-month post ICU discharge) and 3 weeks later. Depression: assessed using Hospital Anxiety and Depression Scale; at initial assessment (1-month post ICU discharge) and 3 weeks later.

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**Table 4: Summary of results from single studies**

Outcomes	Study	Incidence	Number of participants	Quality of evidence: GRADE
<b>Risk of anxiety in patients recovering from admission to the intensive care unit (ICU)</b> Hospital Anxiety and Depression Scale [46] Follow-up: 3 weeks from initial assessment	Knowles and Tarrier [35]	<b>Patient diary:</b> 2 of 18 participants (11.1%) had the likely presence of clinically significant anxiety. <b>No patient diary:</b> 7 of 18 participants (38.9%) had the likely presence of clinically significant anxiety.	36	⊕⊖⊖⊖ <b>very low</b> 1,2
<b>Risk of depression in patients recovering from admission to ICU</b> Hospital Anxiety and Depression Scale [46] Follow-up: 3 weeks from initial assessment	Knowles and Tarrier [35]	<b>Patient diary:</b> 3 of 18 participants (16.7%) had the likely presence of clinically significant depression. <b>No patient diary:</b> 8 of 18 participants (44.4%) had the likely presence of clinically significant depression.	36	⊕⊖⊖⊖ <b>very low</b> 1,2
<b>Risk of memory recall of ICU in patients recovering from admission to ICU</b> Intensive Care Unit Memory Tool [59] Follow-up: 3 months from ICU admission	Jones, Backman [34]	<b>Patient diary:</b> 85 of 162 participants (55%) had recall of delusional ICU memories. <b>No patient diary:</b> 81 of 160 participants (52%) had recall of delusional ICU memories.	322	⊕⊕⊖⊖ <b>low</b> 2
<b>Post-traumatic stress symptomatology in patients recovering from admission to ICU</b> Post-Traumatic Stress Disorder-Related Symptoms Screening Tool 14 [47] Follow-up: 3 months from ICU admission	Jones, Backman [34]	<b>Patient diary:</b> The median post-traumatic stress symptomatology in the patient diary group was 24 (Standard deviation (SD) 11.6) <sup>3</sup> <b>No patient diary:</b> The median post-traumatic stress symptomatology in the no patient diary group was 24 (SD 11.6) <sup>3</sup>	322	⊕⊕⊖⊖ <b>low</b> 2
<b>Post-traumatic stress symptomatology in family members of patients recovering from admission to ICU</b> Post-Traumatic Stress Disorder-Related Symptoms Screening Tool 14 [47] Follow-up: 3 months from ICU admission	Jones, Backman [33]	<b>Patient diary:</b> The median post-traumatic stress symptomatology in the patient diary group was 19 (range 14 to 28) <sup>3</sup> <b>No patient diary:</b> The median post-traumatic stress symptomatology in the no diary group was 28 (range 14 to 38) <sup>3</sup>	30	⊕⊕⊖⊖ <b>low</b> 2

GRADE Working Group grades of evidence

High quality: Further research is very unlikely to change our confidence in the estimate of effect.

Moderate quality: Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

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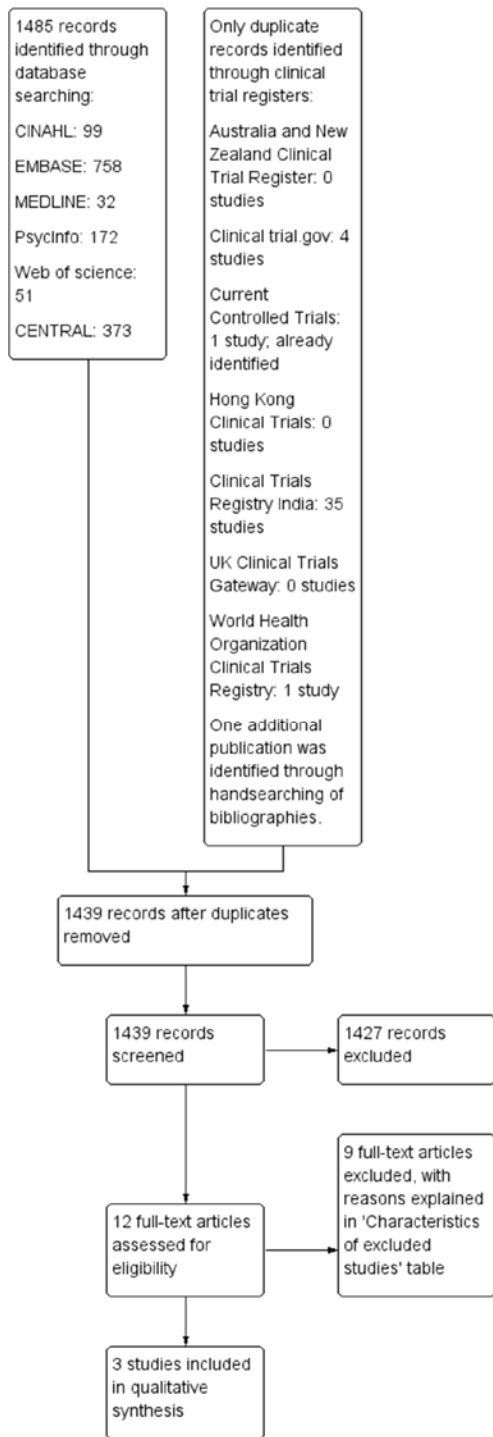
Low quality: Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

Very low quality: We are very uncertain about the estimate.

<sup>1</sup> Results are from a single study at risk of bias regarding blinding of outcome assessment and participants.

<sup>2</sup> Results are from a single study with few patients and few events and thus have wide confidence intervals around the estimate of the effect.

<sup>3</sup> Confidence intervals not provided.



**Figure 1 PRISMA flow chart of study selection process**