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Developing a framework for implementing intensive care unit diaries: a focused review of the literature

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Abstract

Objective—Intensive care unit diaries have been shown to improve post-critical illness recovery, however, prior reports of diary implementation are heterogeneous. We sought to construct a common framework for designing and implementing Intensive Care Unit diaries based on prior studies.

Review method used/data sources—We conducted a focused review of the literature regarding intensive care diaries based on a systematic search of several databases. Two reviewers assessed 56 studies and data were abstracted from a total of 25 eligible studies conducted between 1990 and 2014. We identified key information regarding the development, design, and implementation of the journals. We then grouped elements that appeared consistently across these studies within three main categories: (1) diary target populations; (2) diary format and content; and (3) the manner of diary return and follow-up.

Results—Most studies were conducted in European countries in adult intensive care units and targeted patients in both medical and surgical units. The timing of diary initiation was based on the elapsed length of stay or duration of mechanical ventilation. We categorised diary format and content as: entry content, authors, use of standardised headings, type of language, initiation, frequency of entries, and physical location of diaries. Diaries were hand written and many studies found that photographs were an essential element in ICU diaries. We categorised the manner of diary return and follow-up. The context in which intensive care unit diaries were returned were felt to be important factors in improving the use of diaries in recovery.

Conclusions—In conclusion, we describe a common framework for the future development of intensive care unit diaries that revolves around the target population for the diaries, their format

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and content, and the timing of their use. Future studies should address how these elements impact the mechanisms by which intensive care diaries exert beneficial effects.

Keywords

ICU; Intensive care unit; PICS; Post-intensive care syndrome; PTSD; Post-traumatic stress disorder; ICU diaries

1. Introduction

Critical illness and intensive care can profoundly disrupt the long-term health of intensive care unit (ICU) survivors resulting in new functional or neurocognitive impairments.^{1, 2} This syndrome of new or worsening debilitation after critical care—the post-intensive care syndrome (PICS) is projected to become increasingly prevalent as the general population ages, the use of critical care services increases, and short-term intensive care unit (ICU) mortality continues to decrease.^{1–3} Emerging ICU-based interventions designed to attenuate the impact of PICS seek to restore homeostatic function by hastening the removal of unnecessary organ support devices, decreasing delirium, and promoting early physical activity.⁴

In addition to the functional or cognitive sequelae of intensive care, survivors of critical illness with PICS can also experience high rates of depression, anxiety, and post-traumatic stress disorder (PTSD).⁵ PTSD is a condition triggered by the experiences of a traumatic event that is severe enough to cause powerful subjective responses such as intense fear and feelings of helplessness. Symptoms associated with PTSD can include “flashbacks”—re-experiencing the event and increased arousal.⁶ PTSD can manifest through memories of routine care in the ICU being experienced as fragmented and delusional.^{7, 8} Prior studies have used ICU diaries; a bedside record of significant medical events and procedures recorded with text or photograph entries, to reduce the neuropsychiatric impact of critical care. In a randomised control trial reported by Jones and others, ICU diaries resulted in a significant reduction in PTSD at 3 months after ICU discharge.⁸

In the context of critical illness, diaries could represent an effective, low-cost intervention with prior evidence of high acceptance rates. They may also have benefits that extend beyond the patient since family members of ICU survivors also face high rates of stress, depression, anxiety, and complicated grief.^{1–3} Despite this favourable profile, existing literature does not fully address the framework for using ICU diaries including the handoff and packaging of the diary at the completion of the ICU stay and hospitalisation.

2. Objective

In this focused review of the literature, we sought to construct a common framework for ICU diaries, based on elements reported from individual studies, to aid in the future development and implementation of ICU diary programmes in diverse settings.

3. Methods

3.1. Data sources and search

We systematically searched MEDLINE, PubMed-NCBI, Cochrane CENTRAL and Google using a combination of the following search blocks: 'intensive care diaries', 'intensive care recovery', 'Post-intensive Care Syndrome', 'intensive care journals', 'posttraumatic stress disorder in intensive care patients', 'posttraumatic stress symptoms', and 'rehabilitation after mechanical ventilation.' Additionally, we hand searched the references in each article in order to find additional relevant studies.

3.2. Study selection and inclusion criteria

After initial screening, two authors evaluated the citations for eligibility based on study titles and abstracts yielding a total of 56 potentially eligible articles (Fig. 1). From this sample, studies and publications were excluded if they were not in English, were not published between January 1990 and December 2014, were not relevant to the ICU, and were not original research or literature reviews (Fig. 1). A total of 25 remaining studies were reviewed in detail with data abstraction performed by a single reviewer (M.B.). We used a standardised data abstraction tool to identify key information regarding the development, design, and implementation of ICU diaries, including: author, year, country, single versus multi-center study, study type study subjects, intervention provided in the study, and key findings. Based on this review, we then sought to identify uniform elements that appeared consistently across these studies to design a framework for the implementation of ICU diaries.

3.3. Assessment of quality of reviewed articles

One author (MB) assessed each eligible study for quality using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach. The GRADE approach uses the term quality to refer to an individual study and judgments based about the strength of the body of evidence.⁹

4. Results

4.1. Study characteristics

We divided the eligible studies from our literature search into two categories: (1) studies that primarily evaluated outcomes based on interviews and surveys ($n = 16$); and (2) those that primarily evaluated quantitative outcomes ($n = 9$).

Among the 16 studies we identified as primarily focusing on assessing outcomes with surveys or interviews, most were performed in Europe: Sweden,^{10–13} Denmark,^{14–17} Norway,^{18, 19} United Kingdom,^{20, 21} Switzerland,²² France,²³ Australia,²⁴ and one study conducted Denmark, Norway and Sweden combined.²⁵ Eleven studies were performed in multicentred settings (Table 1). Most studies focused on the ICU patients as subjects; however, 4 studies focused on ICU staff.^{15, 20, 22, 25}

Among the 9 studies we identified as primarily focusing on quantitative outcomes (Table 1), most were from European countries including Sweden,^{26, 27} Denmark,²⁸ United Kingdom,²⁹ France,³⁰ Japan,³¹ and three another enrolling patients from several European countries (Table 1).^{8, 32, 33} There were two randomised controlled studies which enrolled a total of 36 and 352 subjects, respectively.^{8, 29} Quantitative outcome measures used in these studies varied, and included the Therapeutic Intervention Scoring System,¹¹ Hospital Anxiety and Depression Scale,^{19–29} ICU Memory Tool,⁸ Post-Traumatic Stress Syndrome 14,^{8, 32} Peritraumatic Dissociative Experiences Questionnaire 3,³⁰ Medical Outcomes Study Short Form 36,²⁶ Impact of Events Scale, and Acute Stress Disorder Scale.³⁰

4.2. Overview of ICU diary components

Several themes surfaced during our review, which we broadly categorised as defining: (1) the target population served by the diary; (2) the diary format and content; and (3) the timing of diary initiation and follow-up. Within each category, several specific elements could be defined further.

4.3. Identifying the target population

Diaries were implemented in medical, surgical, and mixed ICUs. All studies were conducted in adult ICU patients. Most studies focused on patients whose ICU length of stay was at least 48h; in addition, most focused specifically on those who were mechanically ventilated and sedated. Exclusion criteria often included patients with neurocognitive impairment (e.g., traumatic brain injury, dementia), prior psychiatric illness (e.g., anxiety, depression), or visual impairment as well as those who did not speak the primary language of the respective country in which the study was conducted. Pre-existing psychiatric problems including depression and prior PTSD have a strong potential to exacerbate ICU related PTSD. This remains unmeasured in many mixed ICU studies.

4.4. Diary authorship and medium

Diary authorship was a particularly important aspect of the effective implementation of diaries in ICUs. For example, Jones et al. recognised that the burden of the writing was in starting the diary, in particular, in introducing how the patient came to be in the ICU.⁸ As a result, they used a diary unit consisting of a group of clinicians that were multidisciplinary, including nurses and physicians who were assigned to initiate daily entries. Most studies allowed diverse groups to contribute written material including: ICU providers, patients' family members and friends, as well as the patients themselves. All diaries were handwritten in either a loose-leaf or spiral-bound notebook.

4.5. Diary format, content, and language

In many studies, standardised headings were used in diaries to facilitate relevant entries. For example, Knowles et al. included standardised headings describing the patient's appearance and condition, events on the ward, details of any treatment or procedures, and the names of visitors.²⁹ Other common headings described the inciting events that resulted in the ICU stay, introductory material related to the entry author, and other significant clinical events. Several studies also allowed the recording of entries that were not specifically related to

clinical events. In one study Backman et al. encouraged authors to note everyday routines including patients' reactions.¹¹ Some studies encouraged a standardised time interval between diary entries, for example, either twice or three times a day timed to nursing shifts with additional entries made on a voluntary basis by family and friends. In general, authors were strongly encouraged to use language without medical jargon so that diaries were understood by a diverse audience and so that diaries could be clearly distinguished from the patients' medical record. All the diaries were handwritten using paper format. One study did type up the handwritten diary using Microsoft Word and then bound it into a file and returned to the patient at a visit one week after discharge.³¹

4.6. Inclusion of non-text entries

The most common element across all diaries was the use of photographs, Egerod et al. conducted an interview with 4 patients who received their diaries during follow-up. While they found that significant clinical events were sometimes glossed over by recipients, photos proved essential in helping patients fill in their memory gaps.¹⁶ Akerman et al. also noted that patients found it essential that diaries were amplified by photos with 91% of the patients endorsing that photos helped them understand their critical illness.²⁷ Jones et al. included pictures of patients' pre-ICU life and supplemented these with pictures taken during the ICU stay (e.g., during care procedures) as well as from the patient's perspective (i.e., of the ceiling above the bed).⁸ One study included paintings done by children who could not visit the ICU.²⁰

4.7. Physical location of the diary

In most studies, the diary was kept at the patient's bedside allowing for easy access for the authors and safe transfer of the notebook when the patients were discharged from the ICU. Egerod et al. conducted telephone interviews with ICU nurses to discuss ethical issues related to the diaries and noted that diaries had ambiguous ownership and were neither clearly the property of the hospital nor the patient.²⁵ As a result, the physical location of the diary could potentially result in a compromise of the patient's privacy. No study kept the diary within the medical record or electronically.

4.8. Timing and manner of diary return

There was a high degree of heterogeneity between studies in the timing and manner of the diary return. For example, in some studies the diary was returned to patients at discharge from the ICU or upon discharge from the wards.²¹ In others, diaries were returned as late as 1–3 months hospital discharge.^{16, 32} In the event that the patient did not survive the ICU, one study returned the diary immediately to the relatives.²¹ Diaries were returned both in person and through the mail. When returned in person, for example, the diaries were given to the patient either in the hospital, in the office of their primary care physician, or within a conference room in the ICU.

4.9. Including diaries in ICU follow-up

In many studies, the ICU diary was viewed not only as a physical journal of entries, but also as a conduit for physicians and ICU staff to connect with patients and their families.

However, studies differed in their approach to having patients interact with the diaries. For example, Bergbom et al. had patients read the diaries themselves,¹⁰ while other studies had ICU nurses read the diary entries to the patients over the phone.⁸ Knowles et al. speculated that reading the diary with a professional who demonstrated caring and empathy could enhance the support needed to recover from traumatic events.²⁹ Storli et al. also used the diaries to foster conversations about post-ICU care sometimes coordinated with physical visits back to the ICU.¹⁸ They demonstrated in their study that patients found the conversations and return visits particularly significant. The providers facilitating these follow-up encounters varied between an Intensivist, an ICU nurse, physiotherapist, and family members.²⁹

4.10. Common components of the themes

Review of the themes revealed common components across the studies including: the use of photos, standardised headings, the inclusion of every day events, use of non-medical language in the writings, and keeping the diary at the bedside of the patient. The biggest differences between the studies included: time of diary return and the method in which it was returned. Most studies completed their follow up at six months, with one study extending to 18 months (Table 1). Follow up long term past 18 months is an area where more research is needed to determine the full impact of the diary long term.

5. Discussion

We reviewed the literature to identify a common framework for the development and implementation of ICU diaries. We found that there was heterogeneity between each of the studies with respect to the target population of interest, the format and content within the diaries, and the timing of initiation and follow-up for the diaries. Nonetheless, we were able to identify elements common to most studies and, as a result, describe key considerations for practitioners and health systems to address prior to considering the use of ICU diaries. All the studies to date have excluded patients with previous histories of psychological or mental health problems. The exclusion of these conditions is applicable as most studies are exploring the impact of a diary on memory recall and symptoms of PTSD which would be confounded by mental health problems. Methodologically this is logical, however these patients may be the group that would be at the highest risk of psychological morbidity and benefit the most from an ICU diary.

The most extensive study to date involving six European countries with two ICUs per country is the randomised controlled study conducted by Jones et al.⁸ In this study, ICU diaries were begun after patients had been in the ICU for at least 72h. There was minimal losses after randomisation demonstrating minimal attrition bias in the study. The diary was introduced to the patient by a research person, nurse or physician to ensure the patient understood its contents. Diary initiation was a task assigned to a specific diary group, with subsequent contributions made by nurses and family members. Diaries entries were written daily with everyday language using standardised headings with the inclusion of colour photographs. The diary was then returned to the patient 1 month after ICU discharge and read to them by a nurse over the phone. Follow-up interviews were conducted at 3 month

after ICU discharge. These methods resulted in a reduction in the proportion of PTSD symptoms (5% versus 13% in the control group, $P=0.02$) at 3 months after ICU discharge. The daily entries could provide a journey of the ICU stay filling in gaps that the patient may experience while being sedated or unable to communicate. The daily entries may also serve as recording of world events or local events that occurred during the time the patient was in the ICU. Personal messages of encouragement and sentiment could also be written daily.

While the use of ICU diaries holds much promise, the exact mechanisms by which diaries improve outcomes have not been established. This has important implications for those interested in using ICU diaries as differences in diary implementation could result in different outcomes. For example, several studies intended the diaries to serve as a conduit for enhancing in-person post-ICU care; in this model, the actual content and format of diary entries could turn out to be less important than the personal interaction with providers.¹⁸ The discussion of the patients' ICU stay with an empathic provider adds a component for the patient that validates an ICU stay as being distressing and frightening for a patient. It may also provide a caring aspect and signify for the patient that it personalises their care as a patient in a healthcare system. Storli et al. used the diaries to engage the patient in post ICU care conversations.¹⁸ The patients found this to be significant in their recovery, implying that it may be more beneficial to have the personal touch included in the return of the diary and follow up. Alternatively, the type of patient included for initiation of a diary could strongly influence the potential to decrease post-ICU PTSD. Interestingly, Backman et al. noted that the group who used ICU diaries had better functional recovery at 6 months with some effects lasting to 3 years.²⁶ Others have postulated that the benefits of diaries could be related to patients' gratitude towards staff who 'took the extra step' in their care. Knowles et al. speculated that the restoration of fragmented memories within an autobiographical narrative, based on reviewing the timeline of events in a diary, could be particularly well-suited to treating PTSD based on cognitive models.²⁹

Some studies noted that diary writing as a nursing intervention could be threatened by a lack of funding.¹⁹ These considerations are important because while ICU diaries appear to be a low cost intervention, they still require thoughtful investment.¹³ For example, how can diaries be implemented within clinical workflows to minimise the disruption to providers tasked with recording entries? One possible solution could be assigning a taskforce or group who responsibility is initiate the diary and follow up daily on entries and facilitate the return of the diary. How do practitioners and systems ensure that diaries are kept in a secure location while patients are hospitalized and after patients are discharged? Paper diaries could follow the patient through their hospitalisation and at time of discharge an assigned group could facilitate the process of the return of the diary. None of the studies included an electronic form for a diary, this would eliminate the concern of where to keep the diary during hospitalisation and at time of discharge. Future studies are needed to explore the use of an electronic diary. When secondary authors place entries in the diary, what standards should be in place to ensure that entries are beneficial and not harmful? One study stated that a researcher and two administrative nurses checked the entries by nurses to ensure they were not unpleasant for the patient.³¹ A standardised process when considering the use of an ICU diary is necessary to ensure that entries follow a format that has been approved and reviewed by medical experts in the field of PTSD and memory recall. A policy to educate all staff

needs to be developed prior to considering diaries of any format. What resources are necessary to ensure that post-ICU care, aided by the diary, is adequate and effective? The current literature does not adequately describe the multi-dimensionality of the patient diary interventions. The manner in which the diary is returned and subsequent follow up interventions including length of follow up may contribute significantly to the overall effectiveness of the diary in the recovery process of the patient and the family. There are also implications given that each country has a different healthcare delivery system with different payment strategies for healthcare services rendered.

In addition to these questions, two other concerns became apparent during our review. First, nearly all studies of ICU diaries were performed in Europe. Thus, the framework outlined in our study will likely require adaptation in hospitals based on their cultural milieu, language, laws, resources, and healthcare system design. For example, in the United States, the legal risks associated with practitioners entering data outside of the medical record has been cited as a deterrent to widespread use of ICU diaries in their current format. In addition, what privacy or medical-legal risks could arise from the contents of diaries? These are questions that have not fully been answered in the current literature given that most of the studies have been done in countries where the litigation process is different from the rest of the world. Second, all of the studies utilised hand-written diaries in paper notebooks. With the emergence of web- or app-based technologies associated with personal health records, social media, and health education, the creation of electronic diaries appears to be a natural next step in development. However, electronic tools also have shortfalls potentially related to violations of privacy and the loss of the 'human touch'. A technology-driven model of the ICU diary using personal media devices and allowing patients to use their online blogs to share their experiences may encourage bringing the ICU inner monologue into the mainstream.

Based on our review of existing current studies, we suggest that if diaries are to be considered for ICU patients; patients with an expected length of stay greater than 48–72h be included. Inclusion criteria related to patients' baseline cognition and language barriers may be relevant considerations. Prior studies suggest that multidisciplinary participation is optimal with entries that are initiated by a staff member, occur at least daily, and include subsequent entries by patients' families or friends. Entries can include clinical and non-clinical events written under standardised headings, but should be free of medical jargon helping to make them accessible widely and to distinguish them from the medical record. Photographs of patients prior to hospitalisation as well as in the ICU are consistently thought to be essential for diaries. Diaries should be kept in a safe location and returned to patients after hospitalisation, however, the interval between discharge and diary return is variable. If post-ICU follow-up is conducted, the diary may serve as an important platform through which medical, physical, cognitive, and psychiatric matters can be discussed.

5.1. Limitations

There are several limitations to this review. Studies included in the review were conducted in only a few countries which limits the generalizability of an ICU diary concept. Secondly the quality of the articles was reviewed for bias by one author only. Thirdly none of the studies

explored fully the timing of the diary, training provided to the clinicians writing in the diary, and methods for returning the diary to the patient.

5.2. Education and further research

Current evidence is limited in the methods in which ICU diaries are provided to the patient and family. It has not been established that an ICU diary does not have an adverse effect short term or long term for the patient. Further research in non-European countries needs to be conducted to determine the feasibility of the current studies, and to determine the effect culture and healthcare delivery has on ICU diaries and their outcomes. Legal risks of diaries also needs further exploration. The current studies do not fully explain the education given to the healthcare clinicians and the patient for writing entries into diaries revealing that this is an area that also warrants further research.

6. Conclusion

In conclusion, our review of the current literature resulted in a quality GRADE of low for recommendation of implementing ICU diaries. We described a common frame work for the future development of ICU diaries that revolves around the target population for ICU diaries, their format and content, and the timing of their use. These are important issues that need further research via RCT's. One very important aspect that the studies revealed that was not a common element was the timing of the diary return including the facilitating of reading the diary. As the diary is a very personal account of the patients' ICU visit, patients and their families should be given options of when they would like to receive the diary post discharge, and if they would like to discuss/read the diary with a caregiver or physician. This would personalise the diary further and ensure it was truly patient centred.

There was also no evidence of follow up after 18 months in the studies reviewed. Future studies will need to address how these elements impact the mechanisms by which ICU diaries exert beneficial or potential harmful effects. Use of ICU Diaries have implications for nurses at the bedside. Guidelines of when to initiative the diary and what should be included daily in the diaries need to be developed prior to considering implementation. There are also legal aspects to consider for nurses in terms of writing down medical diagnoses that have not been discussed with the patient previously. Intensive care diaries are an evolving practice and the sustained communication between bedside practice and research is required to test new strategies and their effect on a wider population including many countries and ethnic groups.

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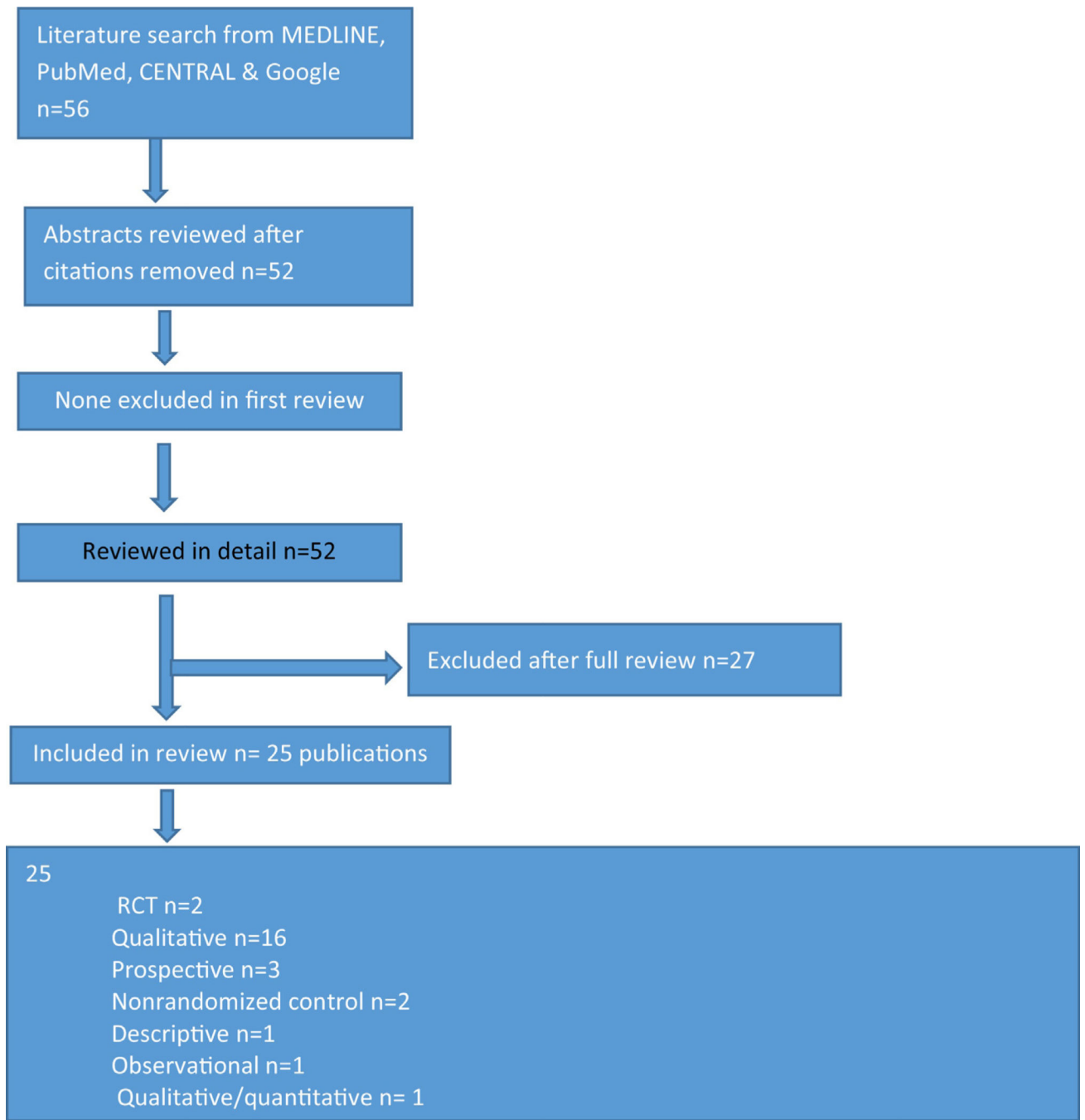


Fig. 1.
Flowchart of literature screening.

Table 1

Summary of included studies.

Source/country	Design/method/multicenter	Aims	Patient/unit	Findings	Interventions	Strengths/limitations
Bergbom et al. (1999) Sweden	Descriptive/Qualitative/No	Importance of diary to patients after their discharge from the ICU and for relatives after a death of a loved one in the ICU	14 ICU patients and families	10 patients and 4 of the 8 deceased patients' relatives answered a questionnaire. All read the diary – 7 said it helped them remember the ICU stay and 2 said it did not. 3 of the relatives said it helped them to return and adjust to everyday life.	Diary kept for 9 months on ten patients together with 8 patients who died later in the ICU Patient selection included those likely to be in the ICU one week or more and who were not awake due to sedative treatment Entries were made three times a day by nurses. No medical notes were allowed in the diary. Diary handed over after ICU discharge and discussed with a nurse one week while patient in the hospital	Pilot study with small sample Follow up past six months
Backman et al. (2001) Sweden	Qualitative/No	Use of ICU diary in debriefing patients and relatives post ICU	51 Diaries	51% of the diaries had been read more than 10 times. 39% of the readers rated them as very positive	Daily account of the patient's progress was written in diary by the nurse. Diary given to patient at a follow up appointment 2 weeks post discharge. Six month questionnaire follow up	Observational study Entries made by nurses only
Combe et al. (2005) U.K.	Descriptive/Qualitative/No	Use of ICU diaries to assist patients understanding of their critical illness	43 ICU patients	Patient's and relatives felt the diaries helped them understand the events of their illness and provided a source of comfort for the bereaved	Retrospective diaries trialled first then Prospective diaries implemented and trailed with follow up at 2, 6 and 12 months post discharge	Entries written by caregivers Follow up extended to 12 months
Egerod et al. (2007) Denmark	Descriptive/Quantitative/Yes	Extent and application of patient diaries in Danish ICUs	19 ICUs	19 out of 48 Danish ICUs use diaries. Diaries used in sedation, ventilated patients and mainly	Diaries have been implemented in Denmark without a plan for the	No systematic follow up The study showed many legal and ethical issues

Source/country	Design/method/multicenter	Aims	Patient/unit	Findings	Interventions	Strengths/limitations
Roulin et al. (2007) Switzerland	Phenomenological/Qualitative/No	To understand the potential benefits of ICU diaries for patients and families	8 ICU diaries	used to assist memory due to post ICU amnesia 4 themes emerged: sharing the story, sharing the experience, sharing feelings and sharing through support	Content analysis of 8 diaries	Prospective diary Long term effects past 2 months not included
Knowles et al. (2009) United Kingdom	RCT/Quantitative/No	Effect of ICU diary on anxiety and depression	36 ICU patients	Positive impact on anxiety and depression scores at 2 months after discharge from the ICU	Prospective diary kept by RN during ICU stay-daily entries	Prospective diary Long term effects past 2 months not included
Egerod et al. (2009) Denmark	Phenomenological/Qualitative/No	Structure and content of patient diaries in Danish ICUs	25 ICU diaries	Data were analysed: extra-case level, case level, diary-entry level, and sub-entry level. Patient diaries acknowledge the patient experience and provide insights into nursing performance	ICU diaries written by ICU nurses	Each case included parallel plots of nurse, patient and family No entries by family members or patient
Engstrom et al. (2009) U.K.	Phenomenological/Qualitative/Yes	Describe patients' experiences of a personal diary written when they were critically ill	9 ICU patients	Themes from the analyses: touching a tender wound: being afraid, deeply touched, appreciating close relative's notes, feeling of uncertainty and gaining coherency	Personal interviews who were formally ill-interview texts analysed	
Storli et al. (2009) Norway	Phenomenological/Qualitative/No	Exploration of the meaning of patients' lived experiences of being followed up in a programme consisting of patient diaries, post ICU conversations and visits back to the ICU	14 ICU patients	The study collaborated earlier research that found patients seek to understand experiences that they have undergone	Field notes were made from encounters with patients during follow up. They were interviewed twice, at about 6 months and 18 months after ICU discharge	Follow up extended to 18 months
Jones et al. (2010) Europe (multiple countries)	RCT/Quantitative/Yes	Effect of diary used using convalescence reduces PTSD	352 ICU patients	Incidence of new cases of PTSD was reduced in the intervention group compared to the control patients	Prospective diary during ICU stay and given at 1 month follow ICU discharge and final assessment of the	RCT Long term effects past 3 months not included

Source/country	Design/method/multicenter	Aims	Patient/unit	Findings	Interventions	Strengths/limitations
Backman et al. (2010) Sweden	Prospective/Quantitative/No	Use of ICU diaries to improve Quality of Life-QoL	262 ICU patients	ICU diaries was associated with improved health-related QoL during the 3 year follow up after a critical illness	development of acute PTSD was made at 3 months 38 patients kept a diary with photos while in the ICU plus a follow up meeting QoL at 6,12,24 and 36 months was compared with the 224 in a control group	Follow up was done past 12 months Non-randomised study
Ackerman et al. (2010) Sweden	Descriptive statistics/Qualitative/Yes	Compare the extent and application of patient's diaries in Sweden	85 ICUs	75% use diaries Discrepancies between different levels of ICUs were detected in patient selection, dedicated staff for follow up and use of photographs. Incongruence between the set unit-goals and the activities for achievement	Telephone interview with ICUs Qualitative content analysis performed to explore the purpose of diary writing	Large National Study
Egerod et al. (2010) Denmark	Descriptive/Comparative/Qualitative/No	Explored why nurses write diaries in addition to conventional charting	25 ICU diaries	Diaries are coherent, personal and supportive. Hospital record is fragment, impersonal and technical	Compared patient diaries and hospital charts to examine what each had to offer patients and the nurse	Entries made by nurses only Small sample size
Egerod et al. (2010) Denmark	Focus group/Qualitative/Yes	The aim of the study was to explore the patients' experiences and perceptions of receiving intensive care diaries	4 ICU patients ICU patients	The diary was not a dependable source of information, did not enhance recall, helped complete the story, pictures were essential, patients need to know how they behaved, widely shared with family. Optimal timing of the diary handover varied due to patient readiness	Triangulated approach combining data from a focus group and intensive care diaries for four former ICU patients Focus group interviews at one month or three months post ICU stay	Triangulated approach increased the internal validity and trustworthiness of the findings Small sample size
Gjengedal et al. (2010) Norway	Descriptive/Exploratory/Qualitative/Yes	Obtain knowledge about the background, extent and implementation	30 ICU nurses	31 out of 70 ICUs offer patient diaries. Most of the ICUs had guidelines for the	Telephone interviews with experienced ICU nurses	Nationwide study of all ICUs

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Egerod et al. (2011) Multiple	Comparative/Qualitative/Yes	of diaries in ICUs providing mechanical ventilation to patients Describe and compare the emergence and evolution of ICU diaries in Denmark, Norway and Sweden	114 ICU nurses	Diaries and the diaries serve two functions: caring and therapy. Writing frequency varies and follow up varies. Diary writing as a nursing intervention was threatened by lack of funding Diaries were introduced in the 3 countries by a grass roots effort by mutual cross national groups. It has evolved into an evidence based domain of inquiry. Study revealed diaries as: therapeutic, act of caring, expression of empathy or a hybrid of all of these.	Secondary analysis of qualitative data generated by telephone interviews with ICU nurses	Study included three countries
Egerod et al. (2011) Denmark	Grounded theory/Qualitative/Yes	Explored how patients and families use diaries in the context of the illness	19 ICU patients and 13 relatives	Patient perspective-information acquisition and gaining insight: relative perspective-supporting the patient, supporting oneself and negotiating access	ICU diaries and handover 1 or 3 months post ICU discharge	Entries made by nurses
Garroutie-Orgeas et al. (2012) France	Prospective with an intervention period between two control periods/Quantitative/No	Impact of an ICU diary on the psychological well-being of patients and relatives at 3 and 12 months post ICU discharge	143 ICU patients and families	Relatives-severe PTSD after 12 months varied significantly across periods. Similar results in the PTSD score after 12 months in the ICU patient	Diary written by ICU staff, patients and relatives of patients	Conducted in a single centre The ICU had already a strong emphasis on family wellbeing for many years Follow up extended to 12 months
Jones et al. (2012) United Kingdom and Sweden	Observational/RCT/Quantitative/Yes	Effect of ICU diary to ICU patients and their relatives in reducing levels related to PTSD in the relatives	30 Relatives	Family members who received their diary at 1 month had lower levels of symptoms related to PTSD at the 3 month follow up than did the control family members	Family members recruited examining the effect of diary outlining the details of the patient's stay in the ICU on the development of PTSD in patients. The family members examined the additional effect	Patient and families included in the study Long term effects past 3 months not included

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Nydah et al. (2013) Germany, Sweden and Switzerland	Prospective/Observational/Quantitative/Yes	Evaluation of time taken by nurses writing in ICU diaries	29 ICU diaries	The first entry in the diary required more time than subsequent ones. Nurses with more experience used more time to write a diary. Mean time differed between countries	During a 6 month period nurses measured the time they took to write a diary in minutes.	Measured time was self-reported
Perier et al. (2013) France	Phenomenological/ Qualitative/No	Exploration of healthcare workers perception of reading and writing in ICU diaries	36 ICU workers	Four themes: Suffering of families, using the diary as a source of information for families, determining optimal interpersonal distance with the patient and relatives and using the diary as a tool for constructing a narrative of the patient's stay	Interviews with staff—two domains explored—reading and writing in the diaries	Individual interviews allowed for in depth insights The data may not be generalisable to ICUs that have long term experience with ICU diaries, the study was done after six months of experience of diaries
Akerman et al. (2013) Sweden	Descriptive explorative/Qualitative/ Quantitative/Yes	Identify the preferred content and usefulness of an ICU diary as described by ICU patients	130 ICU patients	Patients stated that detailed information about daily activities and medical facts had to be included to understand what happened to them	Patients answered a questionnaire and participated in an interview 6 months after discharge from the ICU	Study extended to six months post discharge
Ewens (213) Australia	Descriptive/Qualitative/No	ICU survivors and relatives perceptions of the diaries post discharge from the hospital	18 ICU patients	Most read their diaries but did not write in them after discharge Most viewed them as being positive for their recovery	Patient surveyed at 3, 6 and 12 months post hospital discharge	
Glimelius et al. (2015) Sweden	Descriptive/Qualitative and comparative	Compare patient's memories and PTSD in relation to having received and read, or not and patient's experiences of having received and read their diary, without having discussed the contents with ICU staff	96 ICU patients	Patients valued reading their diaries but did not want to read them with a staff member. At two months there was no differences in PTSD prevalence or within results of the ICU memory tool between the diary and non-diary group.	ICU diaries given at ICU discharge and after 2 months patients answered the ICU Memory Tool—a screening instrument for PTSD and were also asked to comment about the diaries	Study did not extend past 2 months after discharge Confounder could have been the wakefulness of the included patients during their ICU stay leading to clearer memories

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Tomohide et al. (2015) Japan	Non RCT/Quantitative and Qualitative/No	Assess the impact of an ICU diary to relieve stress symptoms after ICU discharge in the short term	40 ICU patients	ICU diaries improved distorted memories and helped relieve acute stress symptoms. Patient admitted to the ICU in an emergency did not find the ICU diary as helpful as asking the nurse directly what had happened	ICU Nurse made entries daily, entries check by researcher and 2 nurse administrators to ensure content was not unpleasant to patient. Diary typed up and handed to patient at one week visit post ICU discharge Patients interviewed in hospital and one week post discharge using anxiety, depression and acute stress disorder scales	First study of its kind in Japan Diary read by researcher and patient during the post ICU visit Small sample size

RCT: randomised controlled trial.