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Title: The use of diaries in psychological recovery from intensive care

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Abstract

Intensive care patients frequently experience memory loss, nightmares, and delusional memories and some may develop symptoms of anxiety, depression and posttraumatic stress. The use of diaries is emerging as a putative tool to ‘fill the memory gaps’ and promote psychological recovery. In this review we critically analyse the available literature regarding the use of diaries for intensive care patients specifically to examine the impact of diaries on intensive care patients’ recovery. Diversity of practice in regard to the structure, content and process elements of diaries for intensive care patients exists and emphasises the lack of an underpinning psychological conceptualisation. The use of diaries as an intervention to aid psychological recovery in intensive care patients has been examined in 11 studies including two randomised controlled trials. Inconsistencies exist in sample characteristics, study outcomes, study methods and the diary intervention itself, limiting the amount of comparison that is possible between studies. Measurement of the impact of the diary intervention on patient outcomes has been limited in both scope and timeframe. Further, an underpinning conceptualisation or rationale for diaries as an intervention has not been articulated or tested. Given these significant limitations, although findings tend to be positive, implementation as routine clinical practice should not occur until a body of evidence is developed to inform methodological considerations and confirm proposed benefits.

Keywords

Intensive care; diaries; psychological status; stress disorder, post traumatic;

Introduction

Critical illness and injury presents multiple challenges to patients and their families. For patients, critical illness presents an immediate threat to survival and physical wellbeing. Patients and their families also need to address the psychological impact of their physical illness, the experience of often painful interventions, the impact of ongoing treatment and rehabilitation, as well as exposure to the intensive care environment.

The combination of critical illness, its treatment and the intensive care unit (ICU) results in sleep deprivation, exhaustion, sedative and opiate use and their withdrawal; all of which may affect patients' short and long term psychological health. Patients recovering from critical illness frequently suffer from memory loss, nightmares, and delusional memories [1] that may continue for some time after discharge. Some patients develop symptoms of anxiety, depression and posttraumatic stress that may be either acute or chronic [2]. The use of diaries for ICU patients is emerging as a putative tool to 'fill the memory gaps' and promote psychological recovery. In this review we critically analyse the available literature regarding the use of diaries for ICU patients to determine the impact of diaries on ICU patient recovery.

What is a patient diary?

Diversity of practice in structure, content and process elements regarding the use of diaries for ICU patients exists. Although there is a range of models used to create diaries for ICU patients, they are generally completed on behalf of the patient with the aim of providing a record of events which occurred throughout a patient's ICU admission. There is also variation in the primary purpose of initiating a diary. Goals

include giving time back to the patient, assisting the patient to work through their ICU experience and providing individual or improved quality care [3, 4]. The use of diaries has been conceptualised as a therapeutic instrument, an act of caring, an expression of empathy, or a hybrid of any of these [5].

The majority of reported diary usage has been within Europe, particularly Scandinavia [3, 5-8] and the United Kingdom [2, 8-11], although diaries are rarely reported as standard practice. Between 40-76% of ICUs' in Denmark, Norway and Sweden have reported using diaries [3, 5, 6], however usage in other countries is relatively unknown. Few guidelines regarding the use of diaries exist. Generally, patients who were sedated and/or ventilated, or admitted to the ICU for a significant period of time were the main recipients of diaries [3, 4, 6, 10], although reported variations include the availability and personal interest of the nurses [5] and diaries not being provided to patients who were either orientated, or had severe cerebral damage, dementia, or developmental delay [6].

Diaries are generally written prospectively and addressed personally to the patient, and generally contain a summary of the reason for admission, a narrative of daily activities and a final note on transfer from ICU [4]. There is little empirical evidence or theoretical foundation informing the content and timing of patient diaries. Some ICUs focussed on the provision of medical information [7, 11, 12], and included technical jargon, while other units focussed on social and environmental events with a light overview of health status using non-medical language [3, 4]. The separation of treatment-related information from the main patient diary has been advocated [4]. Inconsistency in the number of diary entries also exists. Egerod and Bagger [14] noted

that, in the diaries of the four patients they interviewed, one diary had 11 entries, two had four entries and one had three entries. They suggested the potential impact of some diaries may be compromised given the brevity of the record; its brevity may raise more questions than it answers and potentially result in poorer psychological outcomes post-ICU.

Diary entries were predominantly made by the bedside ICU nurse, with family members encouraged to write in some diaries [10, 11]. In one report family members were encouraged to keep a separate diary because family members' points of view were considered important to themselves as well as to the patient [6]. There have been limited reports of non-nursing staff contributing to diaries for ICU patients [3, 6, 7].

Photographs have been included as a contextual clue to encourage memory recall, to help in the replacement of inaccurate memories, to assist in the understanding of the trajectory of the ICU stay and as a tool in a person's acceptance of events [4, 10]. Inclusion of individual patient photographs raises concern regarding privacy, consent and relevance [5]. Reports of specific criteria for use of photographs include using generic photographs to minimise the impact [5] or excluding sensitive photographs such as patients with a disfigured face [3]. The two methods may produce different outcomes in a similar way to that found when using personal scripts of traumatic experiences rather generalised images about trauma. Scripts describing the personal experience of trauma tended to provoke trauma memories with more emotional content [13].

The timing and format for the presentation of the diary also varied, with diaries provided to patients between ICU discharge [4, 17] and up to two months post-ICU [2, 10, 12, 16, 18]. No rationale and no empirical or theoretical support for the timing of diary provision was offered by any authors. Minimal detail is available about the process or level of support offered at the time of providing the diary to the patient [10, 13, 17, 19] despite its preparatory importance to the delivery of the primary intervention. Practice differed between simply putting the diaries on the end of the bed when transferring a patient out of ICU with no discussion undertaken [3, 4, 7], to delivering a coordinated system of follow-up and support for the patients and families, answering questions about the content and counselling the patient if required [2, 18]. An intermediate practice of following up patients to ensure that they understood the contents via a conversation either in person or over the phone was used in the large RCT [8]. A return visit to the ICU, with an opportunity to ask questions of staff, was also described in one study [10]. Providing the diary to the patient with little or no support or guidance is not consistent with the empirical literature on post-trauma psychological early intervention [14] or with theories of cognitive behavioural early intervention approaches post-trauma [15]. These variations in structure, content and processes related to the use of diaries for ICU patients emphasise the lack of an underpinning psychological conceptualisation or rationale for the use of diaries *vide infra*.

Literature search strategy

Studies that focused on the evaluation of a diary compiled for an ICU patient, including diaries compiled by either or both staff and family members of the patient, were included in the review. Ovid MEDLINE (1950 to February 2013), Ovid

EMBASE (1980 to February 2013), EBSCOhost CINAHL (1982 to February 2013), Cochrane Central Register of Controlled Trials (April 2013 issue), and PsycINFO (1950 to February 2013) were searched by one member of the author team (AU). A MeSH term for 'patient diaries' is not available so a combination of the phrases of 'patient diary' or 'patient diaries' was used in conjunction with the MeSH term of 'intensive care units'. Searches were performed without year or language restrictions, but were limited to human studies. From the database searches 43 titles were identified, 13 were removed as duplicates, with 30 abstracts reviewed. Eight studies were excluded as they did not examine patient diaries, and 11 were excluded as the authors reported only descriptive information regarding the extent, application and content of patient diaries, in comparison to an evaluation of their effectiveness. Reference lists of relevant papers were checked for additional studies.

At least two members of the author team (including at least one member with clinical intensive care expertise and one member with psychological or psychiatric expertise) critically appraised each study. All study appraisals were circulated to all team members, with themes developed through email and teleconference communication based on the strengths and limitations identified in the appraisal process.

Effect of diaries on recovery

The use of diaries as an intervention to aid psychological recovery after ICU has been the focus of 11 studies (Table 1). The majority of these studies were descriptive, with only two randomised controlled trials [2, 8]. Inconsistencies in sample characteristics, study outcomes and study methods limit interpretation of this body of evidence.

Sample characteristics

Diaries have been labelled as being for 'ICU patients', however participants in the efficacy studies have varied and have included either ICU patients or both patients and family members; no studies focused solely on family members. Given this confusion we have included all studies where patients were a study participant, but also noted the inclusion of, and considerations related to, family members. The potential benefit of diaries is likely to be different for each of these groups. Family members may feel a need for the patient to know how sick he had been despite the patient not feeling the same need. Alternatively the patient may not have been, interested in the diary but felt relieved 'because the diary could entertain his wife and spare him the involvement' (p. 1926 [16]). The problem of differential effect is further exacerbated by a lack of distinction between feedback from past patients or their family members [17].

The criteria used to identify potential study participants have often lacked objectivity, for example, expected prolonged illness [17], or when the patient and family could potentially benefit from a diary [9]. In contrast, few studies used objective criteria to identify patients [8], although these criteria may have led to relevant sub-groups of patients being systematically excluded. Excluding patients who were too confused to provide informed consent, [8] or patients with pre-existing post-traumatic stress disorder (PTSD) or other psychological issues [2, 8], may have excluded those with the potential to benefit most from receiving a diary post-ICU.

Outcomes

The majority of studies examining the impact of ICU patient diaries have used open ended questions of either individuals or groups, generally in an unstructured or semi-structured interview [9, 12, 16, 18, 19] or questionnaire [17, 20, 21]. Standardised questionnaires or clinical diagnostic interviews of psychological outcome were seldom used although there were exceptions [2, 8, 22, 23], with some assessments conducted in person and some over the telephone [22] or via mail [23]. It is difficult therefore to identify the nature and extent of the impact other than whether patients were satisfied and felt they were a useful memory aid. This lack of standardised outcome assessment is a major omission if the diaries are being used to maintain psychological resilience or to promote psychological recovery.

Interviews have most commonly been conducted 6 – 12 months post ICU discharge [9, 16, 18, 19], with one study extending to 18 months [12] and one study not specifying the time frame [20]. It was not always apparent who conducted the interviews, although in some cases it appears to have been the person responsible for delivering follow-up services, including the diary [9, 12]. The questionnaires that were used were often developed locally, with limited [20] or no reports of validation [17, 21]. The remaining three studies used previously validated instruments to assess health related quality of life (Medical Outcomes Study 36-item short-form) [23], anxiety and depression (Hospital Anxiety and Depression Scale) [2], PTSD Diagnostic Scale (PDS) and Post-Traumatic Stress Symptoms (PTSS-14) [8] and memory recall of ICU (ICU Memory Tool) [8].

With the exception of Backman and colleagues who measured health related quality of life at 6, 12, 24 and 36 months [23], timeframes for outcome measurement were

short. Specifically, Knowles and Tarrier measured anxiety and depression when the diary was provided to the patient approximately one month post ICU discharge and again three weeks later [2]. In this small group of 36 patients both anxiety and depression decreased from one to three months in the diary group, with no change in the control group (Table 1). Jones and colleagues measured post-traumatic stress three months after discharge from ICU (i.e. approximately two months after receiving the diary), however the PDS was not administered through self-report as designed [24] and validated, rather it was adapted as an unvalidated interview [8]. In this large cohort of patients there was a difference found between rates of probable PTSD diagnosis as assessed by the PDS in the intervention group compared to the control group at three months, but given there had been no baseline assessment using the PDS to confirm similarity of the two groups it is not possible to draw reliable conclusions from this finding. Further, using the PTSS-14, post-trauma stress symptoms did not change over time and were similar in the two groups at three months providing no evidence of reduction in PTSD symptoms in response to the diary intervention (Table 1). There is evidence to suggest that patient's psychological health after ICU continues to be problematic beyond three months suggesting this follow-up timeline is insufficient [25-27].

General methodological considerations

Only two randomised controlled trials [2, 8] and one cohort study with a retrospective reference group [23] have been conducted in this area, while other studies were cohort studies. Sample sizes have been small, with 4 [18] to 19 patients [16] in the qualitative studies and 25 [9] to the single large study of 352 patients [8] in the quantitative studies. Samples have usually been from one centre and highly selective, with as few as 10% of the patients in each ICU receiving the diary intervention [2, 8,

17, 23]. Retention rates were high in the two randomised controlled trials [2, 8], 25% in the cohort study with retrospective reference group [23], and generally much lower in the small cohort studies. Potential issues of sample and attrition bias make generalisability difficult.

As discussed earlier the characteristics and dose of the intervention, including number of diary entries, content, detail and style of each entry and frequency of diary reading, have also been highly variable. Content may be added to the diaries by different members of the healthcare team and/or the family, the number of entries in the diary may have been quite small (e.g. 3 – 4) and the number of times the patient read the diary limited. These limitations raise the question of the ‘dose’ of the intervention and whether it is theoretically plausible or empirically supportable that a small dose intervention may indeed actually influence outcomes. We know that patients have limited recall of factual events related to ICU [1] and the diary may offer a means of filling in such memories. However patients themselves do not contribute to the diaries and therefore there are questions of whose memories these diaries represent.

Theoretical underpinnings

Any new intervention must be based on an underpinning conceptualisation or rationale. A fundamental difficulty for diaries is that their use is not targeted to the prevention or treatment of a specific psychological disorder, but to addressing gaps in memory between islets of recall.

Various psychological reactions after ICU admission have been described with PTSD prominent amongst them. For some individuals these psychological reactions may be

associated with events that precede the ICU admission, these could include a traumatic injury, a life-threatening illness, a healthcare intervention prior to the ICU admission or events and factors unrelated to the admission (e.g. pre-morbid life stressors). These other events do not necessarily diminish the potential impact of the ICU admission. Instead they may potentiate any post-ICU reactions.

Much research on autobiographical memory for trauma has been completed and is beyond the scope of this paper (for review see [28]). Experimental evidence suggests high levels of stress could result in highly accessible intrusive images and fragmented, incomplete autobiographical memories. This is echoed in ICU experiences. In both adult and paediatric ICU survivors a relationship between post-traumatic stress symptoms and less factual recall or recall of delusional memories has been reported [29, 30].

Core symptoms of PTSD involve memory, e.g., amnesia and intrusive phenomena; both would be considered potential targets for the provision of information through diaries. No one model or conceptualisation has gained primacy in this area but cognitive models of the aetiology of PTSD have attempted to explain the memory abnormalities seen. Of note, there is substantial overlap between three prominent recent models related to memory function: the emotional processing model [31], the dual representational model [32], and the integrative cognitive model [33]. A comparative analysis has noted that each of these explains factors relating to memory function and its potential abnormalities and processes post-trauma [34]. Any one of these models could form the basis of an intervention for PTSD post-ICU admission. Simplistically, if trying to prevent PTSD and other post-ICU psychological disorder,

diaries as an intervention should only be shared with the subset of ICU patients viewed as being more at-risk for poor psychological outcomes post-ICU [14]. The subset of ICU patients who might benefit from this intervention has not yet been determined, nor has the means of feasibly and reliably determining an “at risk” individual in a post-ICU setting, however the trial by Jones and colleagues [8] does suggest that “at risk” individuals are the only ones to benefit from diary-based intervention.

Clinical Application

The wish to intervene post-ICU reflects the humane desire to help, but it is not always better to do something rather than nothing. As noted elsewhere psychological interventions post-trauma are rarely neutral and may inhibit recovery [35]. It is also likely that what constitutes “helpful” diary information will vary among ICU patients, who are a heterogeneous group similar only in that their illness was critical. It is likely that only a proportion of ICU patients require this intervention and the nature of diaries, their content, the timing of the intervention, and who should be targeted needs to be defined empirically. Diaries may be preventative, encourage resilience or promote recovery but it is not yet known how effective they may be, what elements or approach may be most effective, which patients will benefit and for whom they may have an adverse effect. Post-trauma, chronic psychological maladjustment is not the rule with many individuals recovering their functional equilibrium quickly after brief initial distress [36]; 60-70% of patients do not have psychological disorder 12 months post-ICU. Diaries are unlikely to reduce the risk of PTSD for all and they may increase the risk for some. The controversy and debate regarding psychological debriefing should inform all early interventions post-ICU (e.g., [37]), with diaries

needing to be targeted at those needing them [38], and an awareness that psychological interventions are rarely neutral. Acceptability and satisfaction with diaries should be viewed with caution as acceptability does not equate to effectiveness.

Diaries for patients may, with further research, be shown to be very effective. However, the provision of diaries to ICU patients and its study are in their infancy with more questions raised than answers. Any change to usual practice should demand empirical findings to underpin the proposed new intervention. It can be argued that any intervention that promotes more accurate and complete autobiographical recall with greater understanding of the trauma experience to counterbalance delusional memories could promote better psychological outcomes post-ICU though not all patients will want it and this should be respected and allowed for. The assumption regarding diaries is that the patient needs to know what happened. Properly presented, the provision of information may well be helpful for the patient [39, 40], but it may also confront or limit their previously effective adaptive strategies, confuse the patient with what they remembered and what they have been told or emphasise elements they would otherwise have filtered out. Ordinary forgetting should not be underestimated as a useful human skill and may reflect an event not being particularly memorable or may depend on the emotional state or triggers for the memory [34].

The style of writing in patient diaries also requires consideration. Component analyses of diaries for patients are required to determine what aspects are effective. Should patients be advised how to use the supplied diaries? Should the diaries be written in

the third person or in a phased approach (i.e., part, present and future)? Should they be written in a pragmatic or hopeful manner? No description in the current available literature has addressed these vital considerations for effective use of a narrative approach either to target failures of registration of experience or forgotten, traumatic or dissociated memories. It is likely that ICU nurses would require training and guidelines in this specialist approach, highlighted by the difficulties reported by some nurses in authorship [4].

Though not yet discussed in the literature, it is unknown whether the current approach for diaries needs to be modified to assist patients admitted to ICU with a history of prior trauma or psychological distress. As mentioned earlier, the effect of both of these may result in a cumulative effect on risk for poor psychological outcomes post ICU.

Conclusions

The use of diaries across many countries, their characteristics, who receives them and the methodology of the various studies show a degree of overlap but also significant variation making comparisons challenging. There has been no underpinning rationale with authors suggesting its use is essentially a simple, pragmatic approach, appearing almost steadfastly atheoretical and descriptive. Simple solutions to complex problems can be successful but need careful consideration of diverse issues prior to widespread application.

Studies suffer from small numbers, selected samples, lack of clarity regarding the intervention delivered and in the method of assessment, the outcome measures chosen

and the length of follow-up. Although study findings tend to be positive the methodological limitations suggest implementation as routine clinical practice should not occur until a body of evidence is developed to inform methodological considerations and demonstrate efficacy.

Competing Interests

The authors have no financial or non-financial competing interests to declare

Table 1: Overview of studies

Authors (year), Country	Study Design	Population	Intervention; evaluation	Findings
Backman & Walther (2001), Sweden [17]	Observational	51 patients and ten of their relatives from a single ICU	Diary given to patients two to four weeks after ICU discharge; questionnaire mailed six months later	40/41 patients and all relatives had read diary; 26 diaries read >10 times. 39/51 questionnaires had comments: 13 graded neutral, 11 positive, 15 very positive.
Backman et al (2010), Sweden [23]	Prospective cohort study with retrospective reference group	40 patients from three ICUs	Diary & photos to patient two to eight weeks after ICU discharge, questions answered by ICU team; health-related quality of life (HRQoL) assessed 6, 12, 24 & 36 months after hospital discharge	Diary plus follow-up visit associated with higher HRQoL.
Bergbom et al (1999), Sweden [20]	Qualitative, explorative	Ten patients and four of their relatives from a single ICU	Diary prepared by ICU staff, given to patient on ICU discharge, followup one week later to answer questions; survey to patients after hospital discharge	- Seven (70%) patients stated that the diary helped them recollect events/people from ICU, come to terms with illness/injury. - Three (75%) relatives reported diary had helped them return to everyday life and to understand the seriousness of the patient's illness/injury.
Combe (2005), UK [9]	Qualitative, explorative	25 patients from a single ICU	Diary ± photos prepared in ICU by staff & relatives, given to patients ~6 wks post discharge; unclear when and how evaluation was obtained	- Photos assisted as a 'reality check' when setting goals for recovery. - Diaries helped resolve differences in experience between patients and families. - Enabled patients to 'move on' to normal life. - Mixed feelings by family members of bereaved patients regarding seeing photos of loved one.
Engstrom, Grip &	Qualitative, explorative	Nine patients from a single	Diary ± photos prepared in ICU by staff & relatives, given to	Main theme – 'touching a tender wound', with four categories: being afraid and being deeply touched, appreciating close

Hamren (2008), Sweden [19]		ICU	patients after ICU discharge; unstructured interviews ~ one year later.	relatives' notes, a feeling of unreality and gaining coherence. • Strong feelings and reactions when reading it for the first time, ranging from joy, to sorrow and amazement. Some reported reading the diary felt like going through it all again, being thrust back into that difficult time.
Egerod & Bagger, (2010), Denmark [41]	Qualitative, explorative	Four patients from a single ICU	Diary & photo prepared by ICU staff & relatives, given to patients one month (intervention) or three months (control) after ICU discharge; focus group evaluation.	• Diary was not a dependable source of information because significant events were 'glossed over' or neglected . • Participants agreed that the diary did not stimulate memory or enhance recall, but filled the memory gaps and enabled reconstruction of their story. • Participants disagreed on the best time to handover diary as some patients were ready sooner than others.
Egerod et al (2011), Denmark [16]	Qualitative, explorative	Six individual patients and 13 pairs (patient & their relative) from two ICUs	Diary & photo prepared by ICU staff & relatives, given to patients one month (intervention) or three months (control) after ICU discharge with a 'handover' from ICU staff; focus group & semi-structured interview 6-12 months after ICU discharge	• The handover interview, the diary and the photographs were all seen as a source of information; although the diary did not re-establish memory <i>per se</i>, it helped fill in memory gaps. • Some reported the initial reading of the diary was unpleasant, especially when scheduled 'prematurely'. • Information contained in the diary was considered incomplete, however it did provide a catalyst for discussion with relatives and healthcare workers.
Jones et al (2010), 6 European countries [8]	RCT	352 patients from 12 ICUs	Diary & photo prepared by ICU staff & relatives, given to patients one month after ICU discharge; assessment of PTSD (using PTSS-14) & memory recall of ICU (using ICUMT) at one and three months post-ICU. PDS only administered three months post-ICU	• Fewer probable cases of PTSD using PDS at three months in intervention versus control group (3% versus 13%, $p=0.02$), but no pre-intervention (one month) evaluation of probable PTSD was undertaken to allow assessment of incidence. • No difference was found between patients in the control and intervention groups on the PTSS-14 at one & three months, and no change was found from one and three months in either group, suggesting no effect of the intervention. • Patients in the intervention group with a PTSS-14 scoring above a cut-off of 45 at one month had a significant reduction in the PTSS-14 symptoms score at three months compared to patients

				with the same range of scores in the control group (Fisher's exact test $p=0.04$). Recall of delusional memories reduced equally in both groups.
Knowles & Tarrier (2009), UK [2]	RCT	36 patients from a single ICU	Diary prepared by ICU staff; given to patient one month after ICU discharge by ICU nurse consultant, with questions answered; anxiety and depression (using HADS) assessed at one & three months after ICU discharge	- A significant decrease in both anxiety ($p<0.05$) and depression ($p<0.005$) from one month to three months was identified in the intervention group with no differences between the two time points in the control group. - There were fewer anxious patients in the intervention group at three months ($p<0.05$), but no significant difference in depression.
Robson (2008), UK [21]	Observational	20 patients from a single ICU	Diary & photos prepared by ICU staff & relatives given to patients prior to hospital discharge; survey to all patients who received diary in previous two years	11 (55%) found diary distressing first time they looked at it, with comments including 'realising how ill I had been', 'shocking to know how bad things were', 'photo distressing', 'comments seemed to refer to me as a child'. - All respondents thought it helped make sense of what had happened. - Two (10%) felt unhappy with diary content (friends wrote inappropriate things, photos harrowing, wanted 'happy ending' photo, gaps in content, ended too soon).
Storli & Lind (2009), Norway [42]	Qualitative, hermeneutic-phenomenological	Ten patients from a single ICU	Diary & photos prepared by ICU staff given to patient after ICU discharge, conversations and visits back to the ICU; in depth interviews 6 & 18 months after ICU discharge	- Diary was interpreted as incorporating an aspect of gift giving, displaying caring, strongly emotional and individualistic. - Diary helped discover meaning and connections in patients' experiences. - Texts and pictures confirmed the visitors' presence and loving care as well as helped prompt memories of bodily sensation and realism regarding rehabilitation and recovery.

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